

**HOSPITAL HIGH VIGILANCE IN
INFORMAL CARERS TAKING CARE
OF HOSPITALISED PATIENTS WITH
HEART FAILURE: A
CONSTRUCTIVIST GROUNDED
THEORY**

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Abstract

This study is a constructivist grounded theory study about informal care by caregivers during admission and hospitalisation of patients suffering from chronic heart failure (CHF) in Malta. The informal carers pass through demanding and stressful moments when their relatives are admitted and hospitalised. Understanding this social process could help provide the informal carers with tools in coping with this stressful situation.

This study aimed to develop a substantive theory of informal care by caregivers during admission and hospitalisation of patients with chronic heart failure. The new substantive theory was generated from qualitative, semi-structured, in-depth dyadic face-to-face interviews (informal carers and patients). The researcher interviewed 21 participants (13 informal carers and 8 patients). Data analysis was concurrent with data collection, using constant comparison methods and grounded theory coding. Sampling began as purposive, with informal carers taking care of patients suffering chronic heart failure in Malta, and progressed to theoretical sampling. Data analysis continued until theoretical sufficiency had been reached.

Findings suggest that the informal carers continue to care for possible dangers and difficulties that could happen to their relatives during admission and hospitalisation. The only way the informal carers could still care for their relatives during admission and hospitalisation was to be vigilant. The core category of Hospital High Vigilance based on a symbiotic relationship between the informal carers and patients was co-constructed, explaining the social process of informal care during admission and hospitalisation of a patient suffering from CHF in Malta.

This new theory offers new insight into how informal carers react and cope during a stressful events like admission and hospitalisation of their relatives. Subsequently, the Hospital High Vigilance theory highlights the informal carers' vulnerability and uncertainty. It provides valuable insight into how the healthcare professional could interact, collaborate with, and involve the informal carers in the care of their relatives during admission and hospitalisation.

Keywords: Vigilance, Admission, Hospitalisation, Informal Carers, Heart Failure, Constructivist Grounded Theory

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Declaration

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the author's original work. The thesis has not been previously submitted to this or any other university for a degree and does not incorporate any material already submitted for a degree.

A handwritten signature in blue ink, appearing to read 'P. S. S. S.', is centered on the page. The signature is written in a cursive style with a large initial 'P' and a long, sweeping tail.

19/10/2022

Chapter 1: Introduction

1.1 Introduction

This thesis reports on a constructivist grounded theory generated from a research study about the informal care of patients suffering from chronic heart failure during admission and hospitalisation. For this study, informal care is defined as being given by any relative, partner, friend, or neighbour with a significant personal relationship (Family Caregiver Alliance 2021). Such people provide a broad range of assistance for older people or adults with chronic heart failure (CHF) not only at home but even during admission and hospital stay (Family Caregiver Alliance 2021). This research explored what the concept of informal care during admission and hospitalisation meant to the informal carers taking care of their relatives and illuminated the social process involved. The substantive theory produced from the research explained the core processes regarding informal care of patients suffering from CHF during admission and hospitalisation.

Families and informal carers traditionally provided care for family members, especially during chronic illness and at home (Carr and Clarke 1997). The importance of informal care for the patient has been documented in the literature, and its effect on the economy and the national health system has been examined (Eurocarers 2017). However, the informal carers are themselves in need of being recognised as informal carers with their own needs, which are sometimes not adequately addressed in health policies (Eurocarers 2017).

This chapter introduces the informal care of patients suffering from chronic heart failure (CHF) with an overview of the local situation in Malta. It also includes the significance of the study, the research setting, and the professional and personal motivation driving this research study. There will also be an overview of the thesis structure, indicating the content of each chapter.

1.2 Significance of the study

This research study focused on patients suffering from CHF. CHF is a chronic and progressive condition in which the heart muscle cannot cope with the body's needs for blood and oxygen and does not pump enough blood (European Society of Cardiology [ESC] 2014). CHF was chosen because it is a complex cardiovascular syndrome with an estimated 26 million adults living with it worldwide. Its incidence is increasing worldwide (European Society of Cardiology

[ESC] 2014, Jeon et al. 2010, Bahrami 2014). Caring (which includes healthcare treatment and informal care) for a patient with CHF alone costs, as estimated by the ESC, around €174 billion a year in Western Europe, North America and Latin America (ESC 2014). Malta's direct annual healthcare costs were estimated to be 8 million euros per year in 2005, which could increase to 15.2 million by 2035 (Cauchi et al. 2017). Death due to cardiovascular disease (including CHF and other related disorders) contributed to 40% of all deaths in Malta in 2013 and 38% in 2014 (England 2015, Department of Health Information and Research 2015). Heart failure alone accounts for 5.7% of all deaths and represents the most common cause of death locally (England 2015, Department of Health Information and Research 2015). From the total cost of CHF treatment, 54% is attributed as a direct cost to the national health services (NHS), whereas 24% are indirect costs attributed to patients' productivity losses and 22% due to informal carers' loss of earnings (ESC 2014). These statistics indicate the significant impact of CHF on health services, patients, and informal carers. Due to the severity of the illness and rapid deterioration of the patient's general condition, the survival rate is worse than that of patients suffering from bowel, breast, or prostate cancer (Davidson et al. 2013, ESC 2014, England 2015, Cauchi et al. 2017). Nevertheless, about a quarter of the patients admitted to hospital with CHF are readmitted within a month due to the complications and continuing deterioration in the condition of CHF (ESC 2014, Buck et al. 2015). Readmission can increase the burden on the economy and increase patients' anxiety and even that of their respective informal carers (ESC 2014, Buck et al. 2015).

In Malta, 26% of the total population was reported to take care of their relatives at least once per week (Zigante 2018). In contrast with their European counterparts, where female carers numbers are higher than those of male carers, in Malta, there is an equal distribution of female and male carers (Zigante 2018). This difference could be partly because female labour market participation equals Malta's male labour market participation (Zigante 2018). Furthermore, the age distribution of informal carers as a percentage of the total population is 19% in the age group of 18–34, 33% in the age group of 35–64, and 21% in the age group over 65 years, which is similar to the other European countries (Zigante 2018). These data are important because they present a picture of the majority of informal carers in the working group age. Therefore, hospitalisation could interfere with the lifestyle of the informal carers and their income. The informal

carers could need time off to meet the healthcare professionals, pick up their relatives on discharge, or be near their relatives due to unstable conditions. However, the number of informal carers increases each year worldwide (Carers UK 2015). In the UK, it increased 11% in 10 years (2001–2011), making the population of informal carers over 6.5 million (Carers UK 2015). The number of informal carers in the USA, according to a census in 2015, was above 43.5 million (FCA 2016a).

Furthermore, Carers UK (2015) estimates an increase of 40% in the number of informal carers needed by 2037, which translates to an extra 2.6 million carers in the UK alone. No data or study was found that predicts or estimates the increase in the number of informal carers that addresses the Maltese situation. This increase in informal carers could be attributed to living longer, better treatment, and an increase in chronic diseases (Coleman et al. 2004). Therefore, there is a 3 in 5 chance of becoming a carer at some point during most people's lifetime (Carers UK 2015, FCA 2016b). Consequently, policymakers should provide the necessary resources and practical support¹ to empower the patient and their respective informal carer in the community and during hospitalisation (European Society of Cardiology [ESC] 2014). Therefore, it is crucial to investigate how admission and hospitalisation impact informal carers (Carr and Clarke 1997, Carr and Fogarty 1999, Mor and Beside 2011, Carr 2014).

This PhD study will focus on the informal care of CHF patients while hospitalised, especially during admission, which fits with a policy directive to undertake research that could improve clinical outcomes for CHF patients and their respective informal carers (ESC 2014). Despite the importance of informal carers for patients suffering from CHF, their interest is rarely considered by policies and policymakers (Eurocarers, 2017). This is reflected in the lack of policies that address the needs of informal carers in health and social, education, employment, social security, transport, and housing policies (Eurocarers 2017).

¹ ESC (2014) recommends a timely and accurate diagnosis, treatment, and long-term management through smooth transitions from hospital to community, public awareness of CHF symptoms, and easy access community services such as clinics/outpatients or family doctors.

1.2.1 Informal carers

In view of frequent hospital admissions and the instability of the patients suffering from CHF, informal carers² play an integral part in the patient's life. Families traditionally provided the informal care of other family members, and the majority of the care was provided at home (Carr and Clarke 1997, Carr and Fogarty 1999, Dudley and Carr, 2004). In the early decades of the last century, medical care advancement shifted the locus of care from hospital to home (Carr and Clarke 1997). This medical care advancement emphasised the accelerated discharge process for most patients (Carr and Clarke 1997, Carr and Fogarty 1999, Mor and Beside 2011, Carr 2014, Buck et al. 2015), which benefits the patients by significantly reducing the hospital length of stay. Reducing the hospital length of stay could reduce the rate of hospital-acquired infection, the risk of deep vein thrombosis, and the risk of pressure ulcers due to better quality of sleep and nutrition at home (Carr and Clarke 1997, Carr and Fogarty 1999, Mor and Beside 2011, Carr 2014, Buck et al. 2015). This accelerated discharge may be efficient even for the hospital to increase bed availability and treat more acute patients (Mor and Beside 2011, Carr 2014, Buck et al. 2015). Therefore, a shift is nowadays noted in which care and total recovery is going back to community care and, therefore, back to the informal carers (Mor and Beside 2011, Carr 2014, Buck et al. 2015). However, this accelerated discharge may not be beneficial for the patient because it may contribute towards an increase in the rate of admissions due to various reasons, mainly the unpredictability of the patient's chronic condition and the informal carer's inability to cope with post-discharge care (Mor and Beside 2011, Carr 2014, Buck et al. 2015).

Informal carers of a patient with CHF must therefore be able to respond to the care of their relatives while at home. This care includes a whole range of skilled home care provided daily. These could consist of personal care (bathing, washing, feeding, dressing, managing incontinence and many more), medical care (administration of medication, oxygen therapy, monitoring blood glucose, blood pressure monitoring, diet and eating monitoring and much more), specific communication skills (how to deal with healthcare professionals, and with the patient themselves), and transversal skills (time management, recognition of

² In the context of this study, the terms informal carer, caregiver, partner, spouse, family, relative and friends are used interchangeably.

exacerbation symptoms, problem-solving, transport for appointments and many more) (Mahoney 2003, Rosa et al. 2017).

While caring for their relatives could be an important source of personal satisfaction, informal carers may experience cognitive, emotional, and social imbalances,³ depression, anxiety, and stress (Rosa et al. 2017). The effects of this have been defined as caregiver burden, which originated to represent the demanding responsibilities and a collection of negative attributes faced by the family caregivers at home (Mahoney 2003). An acute episode of a chronic illness which could cause hospitalisation typically involves an intense emotional involvement by the family that ends with illness stabilisation, rehabilitation, or death (Mahoney 2003). However, hospitalisation can be considered a dehumanising ordeal by the family rather than a healing experience (Mor and Beside 2011, Carr 2014, Buck et al. 2015). Hospital policies such as limited visitation time discourage close family involvement with the hospitalised patients (Carr and Clarke 1997). These visitation policies prevent the informal carers from being active members and involved in their relatives' care while they are hospitalised.

Furthermore, during hospitalisation, family members are subject to hospital norms, enter into a different space and environment with unknown individuals, could be considered as observers by the healthcare professionals, and may witness procedures and devices that could be foreign to them (Carr and Clarke 1997, Carr and Fogarty 1999, Carr 2014, Lima et al. 2019). These hospital policies, norms and culture could invoke a subtle but long-term adverse effect on the physical and emotional well-being of the family (Carr and Clarke 1997, Carr and Fogarty 1999, Carr 2014, Rosa et al. 2017, Wong et al. 2019). Furthermore, hospitalisation can result in the separation of family and friends from the patient, change of social status,⁴ and preventing the execution of daily activities, which can interfere with the relationship between informal carers and their respective relatives (Lima et al. 2019). Consequently, this change in the relationship between informal carers and their respective relatives during hospitalisation could result in intense emotions such as anxiety, fear, isolation, and loss of a sense of

³ Such as power issues between hospital staff and the informal carers.

⁴ From being the main carer to being an observer.

time (Salminen-Tounmaala et al. 2013, Ruckhold et al. 2019, Bjork et al. 2019, Wong et al. 2019).

Early involvement of the informal carer's taking care of their relatives during hospitalisation is imperative to shorten hospital stays and reduce readmissions (cost containment) (Carr and Clarke 1997, Carr and Fogarty 1999, Carr 2014). Therefore, understanding the informal carer's needs and experiences during the hospitalisation of their relatives is necessary (Carr and Clarke 1997, Carr and Fogarty 1999, Carr 2014, Mitchell et al. 2019). The informal carers should be seen as the basic unit of care together with the patient, rather than treating the patient and the informal carers separately as individuals (Carr and Clarke 1997, Carr and Fogarty 1999, Carr 2014, Rosa et al. 2017). Therefore, healthcare professionals should ideally support and meet the needs of the informal carers during their respective relatives' hospital stay while empowering both the informal carers and the patients, so the family acts as the link between the healthcare professionals and the patient (Carr and Clarke 1997, Carr and Fogarty 1999, Dudley and Carr 2004, Carr 2014). There is a lack of research concerning the coping experiences and needs of the informal carers taking care of CHF patients while hospitalised (Salminen-Toaumaala et al. 2013, Taverner et al. 2016). Therefore, an investigation of the informal carer's role, experiences, and needs during admission and hospitalisation could help give the proper support and interventions to the patient and their respective informal carers.

This support for the informal carer and further investigation in the informal carer world are needed because family or caregivers have an essential role for the patients they care for and the respective national health services (NHS). There is a lack of a standard definition of informal carers based on other countries' different concepts, cultures, and understanding (Zigante 2018, United Nations Economic Commission for Europe 2019). Some cultures relate the definition of informal care to the obligation for the relatives to provide care which is part of the national law (Courtin et al. 2014). Normative and cultural expectations about caring and gender roles determine what people think of informal care (Zigante 2018). Another definition of informal care depends on the altruistic and reciprocal behaviour of the families, in which informal care goes beyond the normal helping activities within the household (Arber and Ginn 1990). Another possible explanation of this lack of standard definition of informal carers is embedded in

the complexity of the social process involved. Informal care is a social process because:

- Informal carers have a pattern of growth and change in the society over the years as the carers of their relatives;
- Social interaction between informal carer and their relatives, healthcare professionals and other people repeatedly occur, for both the informal carers as individuals and as group interaction;
- And informal carers establish a social relationship with others. Their pattern of behaviour is modified through social interaction (such as a change in working hours, change in social activities and many more). (Zignate 2018, Troisi and Formosa 2004, Carer UK 2015)

Informal care should be recognised as an important social process in the family's life, as it involves cooperation, conflict, competition, accommodation, assimilation, and exchange. Thus, investigating the social process of informal care could help generate a more concise and comprehensive definition of the informal carers taking care of their relatives suffering from CHF during admission and hospitalisation.

One can argue that the NHS, not only in the UK but also in Malta, relies heavily on informal carers' willingness and ability to provide care voluntarily to their loved ones (Troisi and Formosa 2004, Carers UK 2015). Because of this, informal carers support the already stretched healthcare service, without which the NHS would struggle (Carers UK 2015). It is estimated that the informal carers' input in the UK results in a £119bn reduction in costs to the NHS per year, which is more than the total spending on the NHS in England (Carers UK 2015), or the annual budget for the whole country in the case of Malta.⁵ However, although no estimated costs of informal carers' input exist for Malta, the above figure gives a picture of the input and the importance that informal carers could have on the Maltese NHS.

⁵ The total annual budget for the Maltese islands was €5.8bn in 2020 (Public Finance Unit Malta 2021)

1.2.2 Research setting – the Maltese healthcare system perspective

To put this research in an appropriate context, explaining the research setting is necessary. The Maltese NHS is similar to the UK NHS and is free of charge at the point of need for Maltese and EU citizens (Azzopardi-Muscat et al. 2017). Malta has one main general hospital with 800 beds situated in the central part of the island, offering patients services, especially in the cardiac field (Azzopardi-Muscat et al. 2017). It has a catheterisation laboratory equipped with the latest technology, a fully functioning heart failure clinic, a cardiac intensive ward, a cardiac medical ward, a cardiac surgical ward, cardiac outpatient clinics, and a cardiac laboratory. Patients suffering from heart failure have a higher readmission rate than the average national hospital readmission rate (CPU 2017).⁶ Cardiovascular diseases are still the number one killer in Malta and accounted for 38% of all deaths in 2014. Heart failure alone accounts for 5.7% of deaths (Department of Health Information and Research 2015).

Furthermore, every year more patients are being referred to long-term facilities such as homes or residential facilities for the elderly rather than staying in their own homes (Clinical Performance Unit [CPU] 2015). Higher referrals to long-term facilities can be attributed to various factors. Malta is a small country of 420,500 people, with a declining birth rate, increasing life expectancy, and an increasing percentage of older persons (World Health Organization [WHO] 2017). This ageing population generates challenges for the Maltese society to sustain costly and long-term healthcare services. In addition, research estimates that around 70% of the population of the older persons of 65 years and over present with one or more chronic diseases (Kodner and Spreeuwenberg 2002). Due to an ageing population, hospital admission may increase due to various factors, including chronic diseases common in older age (Coleman et al. 2004). During 2012, 43% of hospital admissions that occurred in Malta involved persons older than 60 years, and this number is on the increase every year (Clinical Performance Unit [CPU] 2015). Other factors could be that most governmental health public spending on long-term care is devoted to institutional care services rather than at services provided at home (only 15% of the budget is spent locally in the community) (Zigante 2018). This lack of funding in the community services and

⁶ Patients with heart failure have a readmission rate of 7.04%, compared to the 2.93% of the general hospital readmission rate in Malta (CPU 2017).

the increased ageing population could explain this increase in admissions to hospital and long-term facilities every year. However, another explanation could lie in the world of informal caring. The lack of deeper exploration and explanation in the social process of an informal carer could contribute further to the increase of people in long-term facilities rather than staying in their respective homes. Therefore, a deep examination of the effect of recurrent admissions and hospitalisation of the patients suffering from CHF on the informal carers is needed, as well as how this affects the social process of informal care. It could shed light on the needs of the informal carers in a stressful event like admission of their respective relatives due to instability of the chronic disease. In turn, this new information could be used to devise policies or change practices to help or involve more informal carers.

The Maltese government invests heavily in the healthcare system each year⁷ (Public Finance Unit 2021). In addition to free health services at the point of need, non-governmental agencies like the Malta Hospice Movement help persons with heart failure with end-of-life care and respite care (Troisi and Formosa 2004). Besides that, respite care, in-home respite services, and institutional overnight or day services are available free of charge for the informal carers and patients to use (Troisi and Formosa 2004, Eurocarers 2020). A report conducted by, Troisi and Formosa (2004) specifies that elderly patients benefit from a number of self-help groups, organisations, and services; however, there are no policies or support agencies specific to informal carers in Malta similar to Carers UK in the United Kingdom or Family Caregiver Alliance in the USA. Recently, an attempt was made to organise a supportive group for informal carers in Malta, mainly by Solidarity Overseas Service (SOS) Malta and the Caritas Movement, but this has still not been officially launched. Although social policy reforms were launched in the past years to support informal carers,⁸ a comprehensive strategy recognising and defining carers is still somewhat missing in Malta (Zignate 2018). A study on the social process of informal care during admission and hospitalisation could

⁷ Maltese government expenditure on health increased from €395 million in 2012 to €555 million in 2016 (Public Finance Unit, 2021).

⁸ Higher access to respite care, special carers leave, and better access of carers to education and employment.

help recognise and define carers and thus could help devise a comprehensive strategy for informal carers in Malta.

1.3 Professional and personal motivation

I am a Maltese citizen and started my nursing studies in 1997 at the University of Malta. This PhD's professional and personal motivation arose from my experience as a practitioner and carer. During my nursing studies, informal carers were essential in inpatient care and recovery. However, the exact dimension of an informal carer was never effectively explained, especially in the hospital environment and chronic care. I always felt that something was missing in the context of informal caring.

As a full-time nurse, I needed to consider patients' respective informal carers apart from caring for the ill patients themselves. Experience suggested that informal carers play a crucial role when patients enter an acute setting. I felt that there was a gap in caring for the informal carers as a healthcare professional. Therefore, I had a vital role in bridging formal care in the hospital and informal care at home. It was apparent that there was a need to promote the involvement of informal carers in the hospital environment. This lack of promoting or allowing informal carers' participation in the hospital setting could be due to a lack of policies and available information. However, I felt that it was my duty to talk to the informal carers and try to involve them in the patient's care or make them feel at ease. This sense of responsibility was derived from my professional duty and my role of acting on behalf of patients and their informal carers, who, more often than not, were highly stressed and scared by the hospital environment. Importantly, I firmly believe in the contribution of informal carers. At the same time, while patients are admitted, I have the potential to significantly help in the patient's recovery and prevent further complications both for the patient and the informal carers.

Furthermore, on a personal note, my father underwent two operations, which were uneventful (with no severe or adverse events occurring while in hospital), and he was discharged from the hospital. However, a week later on both occasions, he developed complications which required readmission and an emergency operation leading to further weeks of hospitalisation. Although these

episodes are not directly related to chronic disease, they made me think about what it means to be separated from your loved ones during an acute phase.

Without a deeper understanding of the informal carers' world, I felt limited professionally and personally, especially during the acute phase. I became captivated with what informal carers do, how and why they do it, their input in the life of persons with a chronic condition, especially while hospitalised, the effect of hospitalisation of the patient on informal carers, and the social processes of informal caring. These experiences and considerations, combined with a questioning mind, launched me into informal caring and informal caregivers, especially in patients with CHF during admission and hospitalisation. This research, therefore, explores what the concept and social process of informal care mean to the caregivers during admission and hospitalisation in the context of providing informal care to a patient suffering from CHF. This study was conducted to develop a substantive theory of informal care given by caregivers during admission and hospitalisation concerning patients suffering from chronic heart failure (CHF). As a framework for this study, the methodology of Charmaz's (2014) constructivist grounded theory was used.

1.4 Thesis Structure

This thesis will be structured as follows:

Chapter 1: Introduction introduced the topic of informal caring of patients suffering from CHF, with the significance of the subject, the local context, and a personal and professional motivation justifying this research study.

Chapter 2: Background describes the initial literature review conducted at the beginning of the thesis project to establish what was already known about the informal caring of a patient suffering from CHF during admission and hospitalisation before data collection began. The research questions and aim are then identified to present the study's intention.

Chapter 3: Methodology explains the researcher's philosophical positioning, including a relativist ontology and constructivist epistemology. This chapter also rationalises constructivist grounded theory as the chosen approach, linked to symbolic interactionism and pragmatism.

Chapter 4: Methods discusses and outlines how the researcher conducted the study, using the constructivist grounded theory logic and procedures in sampling, data collection, data analysis, ethical considerations and methodological rigour.

Chapter 5: Findings presents the data collected through an inductive approach by explaining and understanding the process of informal care of patients with CHF during admission and hospitalisation. This is done by presenting the participants' quotes demonstrating the major categories leading to the central organising phenomenon to show the development of the emergent substantive theory.

Chapter 6: Discussion summarises the substantive theory, followed by a critical evaluation to locate the new theory within the extant literature base using the deductive and abductive approaches.

Chapter 7: Reflections and Implications evaluates the substantive theory based upon Charmaz's (2014) criteria for a constructivist grounded theory, including credibility, originality, resonance and usefulness. The study's limitations provide a critical view of the thesis after reflecting on the implications of the substantive theory for clinical practice, informal care, management, education, and further research.

Chapter 2: Background

2.1 Introduction

An initial small-scale literature review was carried out to place the present study in the context of related research work, thereby identifying what was already known about informal care of a patient suffering from CHF during admission and hospitalisation and what needs to be discovered. The intention was to conduct a very basic general appraisal of the literature rather than an exhaustive review that conforms to the constructivist grounded theory methodology of not influencing the emerging theory early in the study (Charmaz 2014, Deering and Williams 2020). Therefore, this oriented the researcher towards a more specific aim and aided in developing research questions and a research design necessary to submit a research protocol for the ethics committee at the beginning of the research journey (Charmaz 2014, Deering and Williams 2020). This chapter consists of the search strategy, the inclusion and exclusion criteria adopted, the main themes identified from the literature found and the research aim, and the questions derived from this initial small-scale literature review.

The use of literature and when to conduct a literature review is a highly disputed area in grounded theory (Charmaz 2014). The initial small-scale literature review enhances the audit trail of how this research evolved from this initial literature review to the presentation of the findings and theory (in Chapter 5) and integration of the literature into the theory in the discussion chapter (Chapter 6). This eventually enhanced methodological rigour, which will be discussed in more detail in the Methods chapter (Chapter 4). Therefore, this literature review conforms to methodological assumptions and decisions of grounded theory of not conducting an extensive literature review at the beginning of the study (see Chapter 3: Methodology). Later, a more comprehensive and focused literature review was conducted based on the emerging substantive theory. The focused literature review, guided by the substantial theory, was assimilated into the discussion in Chapter 6. This will be discussed in more detail in Chapter 3 (Section 3.3.3).

2.2 Search strategies

The scope of this search strategy was to find and examine literature about the care given by the informal carers, caregivers, partners, spouses, or relatives in the context of patients with CHF while hospitalised, especially during the

admission process, in order to gather background information and awareness of the area being investigated. The literature search strategy, key terms and databases searched are summarised in Table 1.

Table 1: Initial literature search strategy

Key Terms and their variants using Boolean Logic using "AND", "OR"	Databases Searched
(Caregiver OR relatives OR carer OR partner OR family OR spouses) AND ("heart failure" OR HF OR CHF OR "congestive heart failure" OR "cardiac failure") AND ("Acute care" OR hospitalisation OR hospitalization OR admission OR readmission)	EBSCO Host (Academic Search Complete, AgeLine, CINAHL Plus, Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, Cochrane Methodology Register, Database of Abstracts and Reviews, Health Technology Assessment, Humanities International Complete, NHS Economic Evaluation Database), Science Direct, MEDLINE, and PubMed

EBSCO host was used because it provides one of the most extensive single indices for searching high-quality studies from reputable peer-reviewed publishers and journals. It has a basic and advanced search option that can be customised, making it easy to use for the researcher. Therefore, the EBSCO host provides a database content with reliable information and unfiltered results to narrow and cluster results specifically to the examined subject. The keywords above and their variants using Boolean logic were limited to the 'title' or 'keywords' or 'subject terms' and, using the above databases, resulted in 230 hits.

The inclusion criteria adopted were papers and reviews that addressed:

- adults suffering from CHF,
- caregivers taking care of a CHF patient,

- admission, hospitalisation, readmission, acute care, long-term care setting, palliative advance home care setting and other settings.

The exclusion criteria adopted were:

- Articles addressing clinical and medical programmes only,
- Articles addressing a clinical intervention only,
- Articles addressing only the patient or healthcare professionals, and not mentioning the informal caregiver,
- Articles focussing only on tools,
- Commentaries, discussion papers, conference abstracts,
- Non-English language papers.

The rationale for the above criteria was to have a more focused review which reflected the informal care of the patient with CHF by the caregiver throughout admission and hospitalisation or in a similar setting. Thus, articles addressing other aspects which were not informal care and therefore did not address or reflect the area under examination were eliminated. Non-English language papers were excluded in this initial literature review to avoid misreporting research evidence due to incomprehension. Basing this initial review only on English language reports could lead to language bias and be considered one of the main limitations of this initial search (Aveyard 2010, Hart 1998).

Literature such as commentaries, discussion papers, and conference abstracts was not used in this review but was used later for discussion purposes. Articles addressing only patients and healthcare professionals and not involving the informal carers were excluded because the study question focused on the informal carers. From the 230 hits, after adopting the eligibility criteria, 14 articles were retained. A summary of the selected articles is represented in Appendix 21. Two hundred and sixteen (216) articles were excluded because they addressed the effect of a clinical programme or a specific medical intervention, or focused on psychometric testing of tools. These papers were excluded from this initial literature review. Still, it was acknowledged that these papers and literature on informal caring for patients with other long-term conditions were used to enhance theoretical sensitivity at a later stage according to the data collected (see Section 3.3.3). This literature search revealed data that were categorised into three important themes in the context of admission and hospitalisation: the changing

role of the informal carer (Lowson et al. 2013, Buck et al. 2015, Fry et al. 2016), their involvement in clinical decision-making (Crist et al. 2006, Patel et al. 2007, Sandford et al. 2011, Doos et al. 2014, Kaasalainen et al. 2013), and the burden of informal caring placed upon the individual carer (Brannstorm et al. 2007, Luttik et al. 2007, Iqbal et al. 2010, Hwang et al. 2011, Yeh and Bull 2013, Bahrami et al. 2014). The Critical Appraisal Skills Programme (CASP 2010a, 2010b, 2010c) tools were systematically used to critique selected research studies.

2.3 Changing roles: the relationship between informal carer and CHF patient during hospitalisation

A research paper (Lowson et al. 2013) was found during the search that explored the changing role of the caregiver while the patient with CHF was hospitalised. Lowson et al. (2013) conducted a study on family members caring for patients with CHF (n=13) and patients with lung cancer (n=14) at the end of life to study the impact of hospital admission on established relationships using exploratory semi-structured qualitative interviews. They interviewed older adults about their experiences in the presence of their informal carers, who 'contributed' to the study. The authors did not specify the informal carers' contribution during the interviews. Furthermore, patients being in need and grateful to their informal carers could have limited the participant's accounts within the interview.

On the other hand, interviewing the patients alone could have led to participants' emotional and physical safety issues. This is because in-depth interviewing by an unfamiliar researcher could be an intrusive method that might revive previous stressful situations or trauma. Having a familiar face (their relatives) could diminish this (Morris 2015). The authors did not justify or rationalize why the patients were interviewed together with their respective informal carers. Lowson et al. (2013) stated that the interviews conducted in the presence of the informal carers 'appear to be candid accounts' (Lowson et al. 2013, p. 1203), but did not describe what measures were taken or how they evaluated the authenticity of these accounts. Therefore, a lack of audit trail was noted in this study. Maintenance and presentation of an audit trail are essential in any research project (Birks and Mills 2015). However, failing to present this audit trail in the article could be because of journals' word limitations on publishing the articles. The study conducted by Lowson et al. (2013) did not examine how the relationship between the informal carer and the patient changed, evolved, or was

interrupted during admission and hospitalisation. The researcher used an exploratory semi-structured qualitative interview and a framework approach by three different researchers as data analysis. This approach could be described as a pragmatic qualitative approach in which a practical approach was used to answer and understand the process of the people involved (Savin-Baden and Major 2013).

Furthermore, an inductive approach was used in Lawson et al.'s (2013) study to answer the study's research questions. The inductive process involves observing the patterns, resemblances, and regularities in the observed experiences to reach a descriptive conclusion (Tidman and Kahane 2003). Indeed, this depends on the aim and design of the study, and not all qualitative research aims at conceptual results; several studies aim to be descriptive. However, in conjunction with the inductive approach, a researcher could use other approaches such as deduction and verification to have more in-depth, abstract and conceptual results that move away from a descriptive account (Savin-Baden and Major 2013, Charmaz 2014).

Lawson et al. (2013) emphasised the importance patients gave to their informal carers by conceptualising them as the 'conductors' who maintained the rhythm of good care throughout the patient's illness trajectory. However, this role of the conductor was lost when the patient was admitted to the hospital when they became 'second fiddle' to the healthcare professionals and when it came to decision-making and influence on care planning. Lawson et al. (2013) gave information on what it was to be an informal carer taking care of their relatives in a hospital setting, reporting that the informal carers continued to maximise their effort to fill gaps in their relatives' care and advocate their relatives' needs. The study reported how informal carers visited their hospitalised relatives every day, provided supplementary or alternative foods, helped with basic care tasks such as brushing their teeth, and challenged the professionals to ensure that optimum care was given to their relatives (Lawson et al. 2013). This resulted in increased self-reported stress by the informal carer and a perceived additional burden (Lawson et al. 2013). Therefore, the study highlights the significance and the effect of admission and hospitalisation of a patient on their respective informal carers. Furthermore, a deeper understanding of the social processes involved in informal care during admission and hospitalisation is needed, which consists of

the relationship between the informal carers and their respective patients, and even the effects the healthcare professionals have on the care of the informal carers.

Two more studies were identified that addressed the changing role of the informal carers and the relationship between the caregivers and patients in the community (Buck et al. 2015, Fry et al. 2016). Buck et al. (2015) conducted a systematic review on the informal carers' role in heart failure patients' self-care. A systematic review and meta-analysis publication are considered one of the most rigorous study approaches that could minimise the risk of bias and provide strong evidence in research about the effectiveness of interventions (Melnyk and Fenout-Overholt 2012). Buck et al.'s (2015) systematic review had a focused research question with narrow parameters, specific and defined inclusion and exclusion criteria, clear applied quality filters, and detailed data extraction using a number of databases and clear and concise keywords. They conducted a systematic review on 17 qualitative and 23 quantitative papers published between 1994 and 2012. However, a limitation of Buck et al.'s (2015) systematic review was using articles published only in the English language, leading to language bias and not capturing all the articles published on the subject.

Furthermore, they used the theory of Self-Care of Chronic Illness (Riegel et al. 2012) as a theoretical framework to map the caregiver's contribution and role from the literature examined. The theory of Self-Care of Chronic Illness is one of the currently well-known conceptualisations of heart failure patients' self-care and practice guidelines. Using this theory could have limited the findings of the review, and by using other theories, the findings might have resulted in a different outcome. Moreover, using a theoretical framework could have helped and focused the researcher on their analysis of the role of the informal carers. Still, it could have also constrained and contaminated the data analysis by imposing preconceived ideas on data (Glaser 1992).

Results suggest that there was an indication that the informal carer plays a significant role in the patient's self-care of their heart failure but do not explain to what extent and how this role affected the patient's self-care (Buck et al. 2015). This suggests that involving informal carers, especially in the clinical area, enhances and strengthens their role as informal caregivers (Buck et al. 2015). This highlights the importance of further examining and understanding the social

process of informal care during admission and hospitalisation by highlighting the changing role of the informal carers during admission and hospitalisation.

Another study conducted by Fry et al. (2016) examined the implication of patients living with heart failure and the impact on everyday life, family support and access to healthcare. Fry et al. (2016) analysed 11 interviews with patients as a part of a broader multi-centred investigation focusing on unplanned hospital admissions. This study involved a secondary analysis of the ten interviews and one set of field notes for an interview that was not audio-recorded. Three researchers read the dataset and the interviews in which an agreement were found about the most prominent themes. These themes were linked with the existing literature, and a framework was identified to examine the dataset, which was revised after two data sets to include new themes that were emerging. This secondary process and data analysis allowed the researcher to explore rich data from the preliminary study from another perspective. This could be one of the main strengths of this study because all data could be examined in different ways according to their relevance and usefulness to the research aims and questions of the study (Charmaz 2014). Thus, this new analysis and interpretation provided a deeper voice and accurately reflected the participants' accounts, which could have been lost in the original, more extensive study.

Furthermore, the data analysis process described above could be, to some extent, compared to the grounded theory essential methods of initial coding and categorisation of data, theoretical sampling, constant comparative analysis and theoretical sensitivity by using literature. On the other hand, Fry et al. (2016) used only one set of interviews as a part of a larger study. This could have limited the data analysis. If the researcher had compared the analysis of the interviews with the whole data set, the patient's perspectives could have been reported slightly differently. This means that the transferability of the data could only be within context and not to the general population.

Although the focus of the interviews was not specifically on informal carers, Fry et al. (2016) revealed that most participants valued their family's role and acknowledged that their families are important to their recovery. The informal carers could contribute to the patients' recovery from the physical and even from the psychological point of view (Fry et al. 2016). Furthermore, Fry et al. (2016) discovered that while participants feel a sense of being a burden to their family,

there is also a sense of reliance as they would be worse if they were alone with no one to help them. This highlights the complex nature of informal caring, which addresses the patient's vulnerability during admission and hospitalisation and the importance of the relationship between informal care and the patient. There was an acknowledgement of causing an increasing burden that the participants did not want to generate on their families. The patients still needed to rely heavily on informal carers to have activities of daily living met (Fry et al. 2016). Although this demonstrates the impact informal carers have on patients, it does not explain which factors hinder or facilitate informal caring during admission and hospitalisation because it addresses only the patient's point of view.

The above papers highlight the importance of family support on patients, care and coordination between care settings, the flexibility required from the informal carers during hospitalisation, and the importance of medical and nursing staff working in partnership with the informal carers. However, the above studies also highlight the need for deeper exploration into the social process of informal care during admission and hospitalisation, and for exploring that transition of place, role, and status and how the informal carers act. Moreover, the scope of this current study was to examine the informal care of patients with different stages of CHF while focusing on how admission and hospitalisation in Malta affect the role of informal care by the caregiver. Participants with varying stages of CHF could result in different data than those at their end-of-life stages. Furthermore, there is a need to identify the role or the role change of the informal carer once the patient with CHF is admitted or hospitalised, and therefore to explore any impacts this may have on the informal carer's identity. As discussed in Chapter 1, it is essential to identify and examine what factors could hinder or facilitate the role of informal carers, especially in a hectic environment such as that of a hospital. Using the different methodology and methods used in the above studies⁹ could reveal a deeper understanding of the social process involved in informal care during admission and hospitalisation by using the inductive approach and even the deductive and verification approaches.

⁹ Lowson et al. (2013) used an exploratory descriptive qualitative study; Buck et al. (2015) used a systematic review; Fry et al. (2016) used secondary analysis of a qualitative data set collection as part of a wider multi-centred investigation.

From the above three studies, only one study (Buck et al. 2015) had informal carers as their main participants. Lawson et al. (2013) used patients as their main participants with informal carers as support, and Fry et al. (2016) used patients' views on their informal care and carers. Although on similar subjects, the three studies had different outcomes and views, as expected. One reason could be that having two groups of people (informal carers and patients) could give another picture of the same social process. Therefore, collecting data from both informal carers and patients could provide deeper and varied information about the social process under examination.

2.4 Informal carers' participation in care planning and decision-making

Caring for a patient with CHF involves complex decision-making for the informal carer (Sandford et al. 2011). Decision-making can be stressful, especially as the disease progresses and the physical and emotional care demands become more difficult (Sandford et al. 2011). Often, caregivers have little preparation for the caregiving role and need support to make important decisions about their family (Sandford et al. 2011). The literature search retrieved one research article (Doos et al. 2014) which focused on the patient and informal carer's experience during hospitalisation; however, this focus was more on discharge and transition of patients with CHF and chronic obstructive pulmonary disease to the home setting. This study utilised a mixed-method approach to understanding CHF patients and carers' views on hospital discharge. They used an adaptive version of the American Hospital Consumer Assessment of Healthcare Providers and Systems questionnaire (HCAHPS 2012, cited in Doos et al. 2014, p.2403) as a quantitative data collection tool shortly after hospital discharge to obtain descriptive feedback about the participants' experience. The authors did not mention how or if the adaptation of the HCAHPS questionnaire was validated.

Validation of this adaptation of the HCAHPS questionnaire in the context of their study would have been necessary because it assesses whether the questionnaire measures what it is supposed to measure (Hale and Twycross 2015). Failing to represent this important information in their article diminishes the credibility and validity of the result. However, another reason for not representing this information might be the journal's word limit. The data from the questionnaire was utilised to identify and construct interview questions for in-depth interviews to provide rich contextual data. Doos et al. (2014) stated that

another reason for conducting the questionnaire was to test out and identify the potential candidates for interviews. The authors did not give information on the experiences the researchers had with quantitative or qualitative methods. Doos et al. (2014) presented a good description of their study's qualitative methods and analysis.¹⁰ The authors gave little information on the quantitative data collection method such as reliability, validity, replication and generalization. A disparity was noted between the quantitative result and the qualitative result representation. The qualitative results were represented by in-depth and rich data, while the quantitative results were represented in a very basic manner with only a percentage difference. This could show that the researcher might have been more fluent and knowledgeable in qualitative methods than quantitative methods. In mixed methods, the researcher or the researchers must be familiar with both methods to conduct a sound and valid study (Savin-Baden and Major 2013). The study was qualitative dominant, but this was not clearly stated.

Fourteen patients participated in the questionnaire, whereas six patients and five carers participated in the interviews (Doos et al. 2014). The authors did not elaborate more on what criteria they chose to identify the participants for the interviews. They did not indicate if the interviews were conducted individually or as a group (i.e., patients or informal carers alone or patients and informal carers together). This study had a small sample size for the questionnaire, and the interviews suggest a limitation on how the results could be applied to the general population. However, the scope of Doos et al.'s (2014) study was not to generalise the data but to capture new knowledge and information which can be used in a more extensive study.

Nevertheless, Doos et al. (2014) highlighted that participation in care planning and decision-making is mainly hindered by a lack of communication by the healthcare professionals and lack of information about the patient's care. Most participants (both patients and relatives) reported feeling like an 'outsider' concerning the discharge process. Due to lack of involvement and communication, participants felt unprepared to go home from the hospital. These barriers of lack of communication, involvement, and information made the

¹⁰ Interviews were conducted by two researchers – one facilitated the interview and the other observed and took notes. Analysis was done by comparing the interview transcripts with the notes taken during the interviews.

participants feel like outsiders (Doos et al. 2014). Therefore, without adequate participation and decision-making while being hospitalised, the patient and the informal carer may refuse to be discharged home, as they may feel unprepared. This unpreparedness could further lead to being readmitted or opting for long-term facility care (Doos et al. 2014).

Furthermore, Doos et al. (2014) suggested that healthcare delivery should be specific to the needs of the CHF patients at critical transition points such as discharge from the hospital. However, they did not make any recommendations for the needs of their informal carers. Furthermore, this study does not indicate differences or similarities in views or experiences of the patients and the informal carers interviewed. The scope of Doos et al.'s study was not to compare the interviews of informal carers with patients or vice versa. Still, a comparison of the two sets of discussions could have resulted in a deeper understanding of the participants' experience. This highlights the importance of examining in further detail the informal caring during admission and hospitalisation, in which constant comparative methods and methodology could be used. The notion of being an outsider in the hospital environment was an important starting point for this PhD research.

Three further studies were identified (Kaasalainen et al. 2013, Crist et al. 2006, Sanford et al. 2011), which discussed participation in the care plan and decision-making in the community and long-term settings. Kaasalainen et al. (2013) conducted an exploratory descriptive study on the experiences of patients and their respective family members with living and dying with CHF in a long-term care facility. The authors interviewed seven residents and seven family members. Nine interviews were held with two patients alone, two family members alone and five with patients and family members together. Kaasalainen et al. (2013) used various methods to increase the credibility of the data.¹¹ Still, they did not discuss how or if data from interviews with one participant differed or was comparable to data obtained from interviewing two participants together. However, the scope of this exploratory descriptive design was not to compare these two sets of data, and to compare them could have moved to a more conceptual level (Charmaz 2016). However, Kaasalainen et al. (2013) reported that the sudden and

¹¹ The authors used member-checking and independent investigators coding.

unpredictable nature of CHF exacerbations often complicates the decision-making of the informal carers. Kaasalainen et al. (2013) argued that support for the family and adequate communication skills could help in the decision-making process to pursue an aggressive approach or a comfort measures-only approach to sudden exacerbations of CHF. The two settings (hospital setting and long-term facilities) were very similar; the informal carers and patients could grow more accustomed to the long-term facility than the hospital setting. This is because they would be unfamiliar with the continuously changing environment of a hospital. Sudden onset of the CHF and consequently a sudden admission to a hospital could occur. Hence, this PhD study intends to explore informal care during admission and hospitalisation, which could result in different outcomes in informal carers' decision-making as reported in the above research.

A grounded theory study conducted by Crist et al. (2006) examined the process by which 23 patients with CHF and their caregivers made decisions to use home-care services. A three-stage theory emerged that described the decision process to use this service: 'taking care of our own', 'acknowledging options', and 'becoming empowered'. Another grounded theory study conducted by Sanford et al. (2011) examined the process of decision-making among caregivers of patients with CHF by interviewing 20 participants while in the community. They constructed a theory consisting of six phases. This theory explained the decision-making amongst caregivers along the whole trajectory of their disease: actualisation of the issue, problem, or challenge; seeking information, input and support; reflecting on decision choice; evaluating decision choice; and seeking validation. These theories could explain the processes involved in decision-making by the informal carers, especially regarding access and support. They could help to give some theoretical sensitivity when and if the current PhD study data indicates the need to focus on decision-making processes during admission and hospitalisation and how this could affect their informal care. The two theories highlighted above (Crist et al. 2006, Sanford et al. 2011), although conducted in the same settings (community), resulted in two completely different theories which gave a starting point for this study on how decision-making social process could affect the informal carers during admission and hospitalisation. Therefore, although there was limited evidence that validates how decision-making occurs between informal carers and patients with CHF, especially in the hospital,

decision-making will eventually affect the role and the burden of the caregiver (Crist et al. 2006, Sanford et al. 2011).

2.5 The burden of being/becoming an informal carer

Another important theme found in the literature was the burden experienced by the informal carers while taking care of patients with CHF. Iqbal et al. (2010) conducted a longitudinal study on the factors affecting health-related Quality of Life (QoL) in CHF patients and their caregivers and the impact of QoL on clinical outcomes over three years. The study was conducted in a hospital setting with 179 patients and 131 carers using established CHF-specific QoL questionnaires.¹² Then a follow-up of the participants for three years was undertaken to assess the subsequent hospitalisation and mortality rate. Iqbal et al. (2010) suggested that patients who have a higher New York Heart Association (NYHA) classification and low level of social support have a lower QoL, resulting in repeated hospitalisation and an increase in mortality rate. As a result, repeated hospitalisation will affect the QoL of the informal carers and could increase the burden (Iqbal et al. 2010). Results of the study (Iqbal et al. 2010) suggested the importance of the relationship between informal carer and patient on readmission and QoL for both patient and informal carer. Unfortunately, Iqbal et al. (2010) did not go deeper into the relationship between informal carer and patient because their study aimed to quantify this using established instrumentation. Using other methods and tools like in-depth interviewing of the informal carers and/or their respective patients could explore the relationship between the informal carers and their respective patients in more depth. The current study explores how the relationship between informal carers and patients was affected by admission and hospitalisation.

A qualitative study conducted by Patel et al. (2007) explores the factors related to patients seeking care for worsening CHF. Patel et al. (2007) conducted face-to-face semi-structured, open-ended interviews with 88 participants. A sample size of 88 participants could be seen as a large sample in a typical qualitative study. A large sample size in a qualitative approach could produce too much material to analyse effectively (Bryman 2008). However, the sample size

¹²Questionnaires used European QoL-5 Dimensions and the Minnesota Living with Heart Failure Questionnaire (cited in Iqbal et al. 2010, p. 1003).

depends on achieving data saturation when the researcher is no longer collecting new information (Savin-Baden and Major 2013).

On the other hand, an experienced researcher could achieve data saturation in fewer interviews than a novice researcher because an experienced researcher could be more theoretically sensitive to the subject or the research methodology (Bryman 2008, Charmaz 2014). From Patel et al.'s (2007) publication, there was no indication of the researchers' experiences or how data saturation was achieved, making this one of the significant limitations of this study. Patel et al.'s (2007) study interviews were conducted in the emergency department or the ward. The authors indicated that the interviews were conducted during hospitalisation. Although informed consent was obtained from the participants, interviewing participants during an acute phase could have increased the participants' stress or exacerbated the symptoms of the illness. Patel et al. (2007) found that patients do not want to trouble or burden their relatives even in the acute phases. Therefore, the patients did not inform their relatives if their condition deteriorated (Patel et al. 2007). This could lead to a delay in treatment which could result in fatal consequences (Patel et al. 2010). Results suggested that most patients with CHF were aware of the increased burden that might be endured by their relatives (Patel et al. 2010). However, this delay in treatment was an important starting point in this PhD study. The delay in treatment needed to be explored further to examine what other factors could have delayed the treatment of patients with CHF and how this could affect the informal carers during admission and hospitalisation.

In a descriptive correlational study by Yeh and Bull (2012) to examine the influences of older people's activities of daily living while hospitalised with CHF on dependency, a resiliency model of family stress, adjustment and adaptation was used as a theoretical framework. Data were collected using structured questionnaires based on various established instruments.¹³ The population consisted of 82 family caregivers and 82 older people from two hospitals in the USA. The response rate was 58%, resulting in 50 family caregivers and 50 older

¹³ Instruments used were Index of ADL (Katz et al. 1963), JAREL Spiritual Well-Being Scale (Hungelmann et al. 1996), Carers' Association of Managing Index (Nolan et al. 1995), Care Continuity Scale (Given et al. 1992), Care Reaction Assessment (CRA), Caregiver's Esteem Subscale (Given et al. 1992), and Lack of Family Support Subscale (Given et al. 1992).

people. A power analysis was undertaken to calculate the sample size, and the study was powered at 0.86, which yielded a population correlation of 0.40 for a sample size of 50 participants. Yeh and Bull's (2012) study did not provide insights into the interrelationships of the stressor and family caregiver burden over time from admission to discharge and the impact on the continuity of care.

Furthermore, the sample consisted only of spousal caregivers; other caregivers such as children, neighbours or friends were not included. Yeh and Bull (2012) recommended that family carers and nurses work together to improve the quality and continuity of care for the patients by involving the informal carers in the patients' care plan and decision-making, to lessen the burden. Given this, the current PhD study aimed to interview caregivers who may be the patient's children, neighbours, partners, or friends rather than only spousal caregivers who might have presented different experiences.

Other studies have examined the burden of caregiving on the patients' families in different settings such as the community (Hwang et al. 2011, Bahrami et al. 2014, Luttik et al. 2007). Luttik et al. (2007) examined the caregiver burden in partners of patients with CHF using a cross-sectional design. They had a sample of 357 participants and used a questionnaire on caregiver burden. In comparison, Hwang et al. (2011) explored the impact of caregiving for patients with heart failure on the patients' families using a cross-sectional descriptive design with a convenient sample of 76 patients and 76 caregivers. Moreover, Bahrami et al. (2014) examined the caregiver burden among Iranian heart failure family caregivers using a descriptive exploratory qualitative study. The population of this study consisted of 18 family caregivers using face-to-face semi-structured interviews. Although the studies were conducted with a different study design (two cross-sectional and one descriptive exploratory qualitative study) and conducted in different countries (Iran, the USA and the Netherlands), all had similar results. The studies revealed the need to support caregivers, especially immediately after hospitalisation, but ideally also while the patient is hospitalised. Such support could minimise the negative impact of caregiving on the carers. The above studies did not elaborate on how, why, and what affects the support needed by the caregivers during admission and hospitalisation.

Furthermore, Brannstrom et al. (2007) elaborated on the importance of continuous support for family carers while in the community. They conducted a

phenomenological-hermeneutic study on being a close relative of a person with severe chronic heart failure in palliative home care. Brannstrom et al. (2007) stated that having the support of the healthcare professionals during the end stages of the patient's life while at home after hospitalisation could relieve the burden by sharing the responsibility between the informal carers and the healthcare professionals. However, participants still expressed being constantly worried, worn out, and struggling to keep everyday life as normal as possible (Brannstrom et al. 2007). The sample size of this study was 3 participants, which may not have led to category saturation.

On the other hand, a hermeneutic phenomenological study is about giving full attention to an individual story each time before moving to the next story (Savin-Baden and Major 2013). However, in this case all participants were interviewed for the second time. The authors highlighted how the second interview yielded more rich information, which could be explained by a better rapport between the researcher and the participants. Although similar effects on informal care could be observed from the informal carer in the hospital environment, it does not explain how this burden or relief of burden affects decision-making and the changing role of the informal carer while hospitalised.

2.6 Summary of the initial literature search

Most of these reviewed studies mainly focused on discharge or transition from hospital to home or another setting, or are set in another setting (community and long-term facility). Some studies focused on diagnoses and decision-making that lead to hospitalisation. Others focused on anticipated influencing factors, which shed light on only a small part of the bigger picture of the research area under examination. Most of the above literature did not investigate the often-stressful account of the sudden onset of the acute symptoms of CHF, the admission process, or the patient's instability while at a hospital. Furthermore, an established theory is missing from the literature to explain and address the social process of informal care by caregivers during admission and hospitalisation for patients suffering from CHF. Nevertheless, this chapter enhanced the researcher's theoretical sensitivity (see Section 3.3.3). It served as a starting point for the present study on the social process of informal care while a patient with CHF is admitted and hospitalised, by bringing up the following points:

- The literature highlighted the relationship between the informal carers and their respective patient as essential and valued by both (Lowson et al. 2013, Fry et al. 2016). However, the literature did not detail this relationship between informal carers and their patients and how this was affected by healthcare professionals during admission and hospitalisation. Moreover, the effects of the healthcare professionals on the care of the informal carers and the relationship between informal carers and patients during admission and hospitalisation are essential not only for the patients' care but even for the informal carers' well-being and the healthcare system (Lowson et al. 2013, Fry et al. 2016, Doos et al. 2014).
- There was a change in the role of the informal carers during admission and hospitalisation, but the literature did not explain to what extent (Buck et al. 2015, Lowson et al. 2013, Frey et al. 2016). However, the literature highlighted the importance of involving the informal carers in the clinical area to strengthen their informal caregiver role and minimise the feeling of being an outsider (Buck et al. 2015, Lowson et al. 2013, Doos et al. 2014). But literature did not link the role change of informal care and the relationship between the informal carers and their patients and how these affect each other.
- The informal carers should be supported by including them in the decision-making process, affecting the caregiver's burden and role (Kaasalinen et al. 2013, Crist et al. 2006, Sandford et al. 2011).
- The burden to the informal carer could increase if the healthcare professional does not support or recognise the informal caregivers (Hwang et al. 2011, Bahrami et al. 2014, Luttik et al. 2007, Iqbal et al. 2010, Yeh and Bull 2012, Brannstrom et al. 2007). To not burden their informal carers, the patients might fail to inform them about their problems, which could lead to a delay in care (Patel et al. 2010). Delay in care could result in a catastrophic effect on the health of a chronic patient. Addressing this problem is important to minimise complications and possible death, which was not explored in the reviewed literature.
- A methodological approach that includes induction, deduction and verification methods could lead to a deeper understanding of the social process involved in the informal care during admission and hospitalisation, which could consist of a role change, a change in the relationship between

informal carers and patients, the burdening of hospitalisation on the informal carers, and support needed during admission and hospitalisation.

2.7 Research aim and questions

The initial literature review acknowledged background information about the informal care of a patient suffering from CHF during admission and hospitalisation. Without research into the informal carers' understanding of and concerns about their care of their relatives during admission and hospitalisation, there is a risk for hospital policies and programmes to be ineffective and thus result in readmissions and financial burden on both the NHS and informal carers. Furthermore, the researcher's personal and professional motivation and the significance of the study (highlighted in Chapter 1) demonstrated that research is needed, especially in the Maltese context, exploring the following aim and research questions:

Aim: to develop a substantive explanatory theory of informal care by caregivers during admission and hospitalisation of patients with chronic heart failure.

Research questions:

- In what way does the hospital admission process of patients suffering from CHF impact their respective informal carers?
- In what way does the hospitalisation of patients suffering from CHF impact their respective informal carers?
- What are the importance and meaning attributed by the patient with CHF to their respective informal carers during admission and hospitalisation?

Chapter 3: Methodology

3.1 Introduction

Chapter 2 outlined the research aims and questions to explore and examine the social processes of informal care by caregivers during admission and hospitalisation concerning patients with heart failure. Consequently, this chapter explains the philosophical positioning of a relativist ontology, constructivist epistemology and constructivist grounded theory methodology with the additional influence of symbolic interactionism and pragmatism. Then an explanation of why a constructivist grounded theory methodological approach was chosen, along with a discussion and a general overview of the different types of grounded theory is explored. This will explain why grounded theory research was the most suitable type of study to address the research questions and aims.

3.2 Philosophical perspective

3.2.1 Philosophical positioning

The type of knowledge sought by the research questions highlighted in the previous chapter assumes multiple realities. As stated in the earlier chapters, the informal care of a patient with CHF is usually complicated. Informal carers face a number of emotional and practical issues during the lifespan of the chronic disease (Buck et al. 2015, ESC 2014). This complex situation can be further complicated during an acute phase resulting in admission and hospitalisation, where informal carers face psychological distress, and their usual lifestyle is on hold (Levine 2002, Giles and Hall 2014). Nevertheless, during admission and hospitalisation, informal carers could be influenced by their respective past experiences as informal carers, the Maltese and hospital culture and their respective values. Therefore, as a researcher, I examined the participants' standpoint, past, and social circumstances (Charmaz 2009).

Furthermore, an informal carer's meaning of informal care during admission and hospitalisation may be different compared to another informal carer or patient passing from the same experiences (multiple realities). The health needs of patients with CHF and their informal carers are complex and involve several holistic elements such as the patient's and informal carer's psychological and physiological self (Levine 2002, Giles and Hall 2014). Furthermore, participants are in different age groups, have different relationship statuses with the CHF patients (daughter, son, husband, wife, friends, partner), and different

backgrounds (socio-economic, professional, educational). Patients are in various stages of chronicity which influences the meaning they give to informal care. Additionally, the literature reviewed in previous chapters indicates that patients with CHF tend to experience a rapid deterioration in their general condition due to the severity of the illness and higher readmission rates compared to other diseases (Davidson et al. 2013, ESC 2014, CPU 2017). Thus, this could influence the informal carers' and patients' experiences and social process of informal care during admission and hospitalisation. Therefore, the multiple realities inherent in this research reflected a relativist ontological position that recognises that reality for informal carers and patients is value-laden and involves the individual's subjective interpretation as influenced by culture, context, and past experiences (Charmaz 2014). Furthermore, during this study, I acknowledge that informal carers' and patients' reality is multiple constructions influenced by the situation, culture, and experience (Charmaz 2014).

Consequently, this research adopted a constructivist epistemological position by emphasising interrelationships between the researcher and participant and the co-construction of meaning (Charmaz 2014). By adopting a constructivist approach, I acknowledge that I cannot separate myself and my experiences from the research or be entirely objective about the data. My past experiences, values, priorities, positions, and actions affected the outcome of this study (Charmaz 2009). Therefore, from a constructivist approach, findings result from mutual construction of the experience through interaction between the researcher and the participants (Charmaz 2009, 2014). Because of this, the final representation of the substantive theory will be partial, conditional, and situated in a particular time, space, position, action, and interaction (Charmaz 2009). Therefore, I acknowledge that I am a nurse who has worked closely and provided support and information to informal carers and patients suffering from CHF. In addition, I have personal experiences of being an informal carer of my father in the past and even presently. Therefore, along with the preliminary literature review and past professional experiences with informal carers of patients with CHF, being an informal carer myself has given me an insight towards informal care during admission and hospitalisation. By following a constructivist approach, I acknowledge that these past experiences and previous exposure to the informal care world are an added value rather than a limitation, and were used as a source

of theoretical sensitivity (which will be explained further in Chapter 4) (Charmaz 2014, Gentles et al. 2014).

However, as a researcher, I managed to reflect on my personal views, perceptions, and opinions based on my experience by using reflexivity (Charmaz 2014, Gentles et al. 2014). Reflexivity was used as an integral part of the entire research process rather than as another source of data (Charmaz 2009). Therefore, in this study, reflexivity involved scrutinising my research experiences, decisions and interpretations, and how these helped me during the entire research process (Charmaz 2014). Being reflective helped me be open to hearing and relating to the participants' views (Charmaz 2014, Gentles et al. 2014). Consequently, data was enriched by my position as a co-producer. Through my interpretation and reflexivity, it was possible to sensitise myself to the participants' main concern about informal care during admission and hospitalisation (Charmaz 2014, Gentles et al. 2014). Further discussion about how reflexivity enhanced this study can be found in Section 3.3.3 and Section 4.6.2.1.

3.2.2 Symbolic interactionism and pragmatism

A constructivist approach could draw from symbolic interactionism (Holloway and Galvin 2017, Charmaz 2014). It is a theoretical perspective that explains and focuses on human interactions, meanings, actions, and adaptations to their daily lives (Holloway and Galvin 2017, Charmaz 2014). This study used symbolic interactionism to raise theoretical questions about the data. Symbolic interactionism brought logic and assumptions to the methods and data analysis, as explained below and in Chapter 4 (Charmaz 2014). A fundamental feature of symbolic interactionism is that humans cannot be separated from the contexts they live, interact and act in (Handberg et al. 2015, Charmaz 2014). Therefore, by having its roots in symbolic interactionism, constructivism was an appropriate epistemology to address the research questions because it focuses on an active process and meaning created from social interaction – in this study, the informal care during admission and hospitalisation (Carter and Fuller 2015, Milliken and Schreiber 2012, Charmaz and Belgrave 2013). As a social theory, symbolic interactionism originated from the pragmatist tradition and the Chicago School heritage of George Herbert Mead and, more particularly, with his student Herbert Blumer (Charmaz 2014, Sandstrom 2014). Blumer (1969) established three

fundamental aspects of symbolic interactionism, which were applied to this research study as can be seen in Table 2.

Table 2 Blumer (1969, p. 3) symbolic interactionism premises

Symbolic interactionist assumptions	Application to this study
Human beings act toward things on the basis of the meanings that things have for them.	Informal carers and patients have their own meanings of admission and hospitalisation in relation to their relatives with CHF.
The meaning of such things is derived from, arises out of, the social interaction that one has with one's fellows.	The meaning informal carers and patients hold during admission and hospitalisation for their relatives with CHF will come from social interaction with other people and institutions (other relatives, hospital staff, other patients, other informal carers, hospital regulations, hospital environment, and many others).
These meanings are handled in and modified through an interpretative process used by the person in dealing with the thing he encounters.	Informal carers are human beings actively engaged with the people and things involved with taking care of their relatives with CHF during admission and hospitalisation.

Furthermore, Charmaz (2014) extended, clarified, and applied Blumer's assumptions to the constructivist grounded theory, all of which is represented in Table 3 and compared to the current research study:

Table 3: Symbolic interactionism premises as interpreted by Charmaz (2014, p. 270–271) and their application to the present study

Symbolic interactionist assumptions	Application to this study
Meanings are interpreted through shared language and communication.	The meaning of admission and hospitalisation is voiced through various means such as verbal

	language, expressions, emotions, and body language, symbolising the construction of what admission and hospitalisation mean to informal carers taking care of their relatives with CHF.
The mediation of meaning in social interaction is distinguished by continually emerging processual nature.	The social process will influence the admission and hospitalisation of patients with CHF and their respective informal carers.
The interpretive process becomes explicit when people's meanings and/or actions become problematic or their situations change.	Informal carers' main concern about admission and hospitalisation of their relatives with CHF and their actions will impact and be influenced by the meaning they hold for this concern.

In other words, according to Blumer's and Charmaz's premises related to symbolic interactionism, social life is mainly expressed through symbols (Blumer 1969, Charmaz 2014). One way to represent the present-day symbolic interactionist is language (Annells 1996). By using in-depth interviews, the informal carers and patients could express their views and concerns about the process of admission and hospitalisation through their language and expressions (see further explanation in Chapter 4). Using symbolic interactionism acknowledges that the informal carers and the patient have a reciprocal relationship, not one-way determinism (Annells 1996, Blumer 1969). They could cope with the admission and hospitalisation and handle various factors, and in doing so, they had to forge and direct their line of action (Annells 1996). Symbolic interactionism is about micro-sociological theory, which tackles the question of the individual (informal carer) in society (as an informal carer during admission and hospitalisation) (Annells 1996), the relationships between individual perceptions (their patients/relatives), collective actions (healthcare professionals), and society (healthcare system) (Annells 1996).

A pragmatic view was used with symbolic interactionism, which provided further theoretical insight into the researcher's constructivist point of view. Considering a pragmatic view means no certainty, truth is conditional, and reality is fluid with multiple perspectives (Ritzer and Stepnisky 2014). In other words, 'the construct of knowledge is an interpretive rendering of the worlds we study rather than an external reporting of the events and statements' (Charmaz 2014, p. 339). This implies that the researcher and the context are included and acknowledged in the processes, actions and interactions between the individuals who dynamically build the social process that they are interested in (informal care during admission and hospitalisation of their relatives with CHF in Malta) (Charmaz 2014, Birks and Mills 2015) It could be done only by immersion¹⁴ into the informal carers' social processes, which allows for further acquisition of intimate familiarity with the studied social process¹⁵ by constructing and acquiring first-hand knowledge by means of interaction with the research participants. Given this, the pragmatist underpinnings of symbolic interactions together with relativist ontology and constructivist epistemology imply that I had to start the study from an open-ended theoretical perspective guided by a sensitising concept as a researcher. This is reflected through the personal motivation and experiences presented in Chapter 1 and reflected in the initial literature search and the research questions presented in Chapter 2 (Charmaz 2014, Bryant 2017). These sensitising concepts are specified and integrated but modified and redefined during the research process (as seen in Chapters 4, 5 and 6) (Charmaz 2014, Bryant 2017). Furthermore, I had to emphasise the social process, problem-solving, and practical applications of the informal carers' ideas and the social process involved during the admission and hospitalisation of their relatives by invoking abductive logic with the data and the participants, which will be explained in Chapters 4, 5 and 6 (Charmaz 2014, Bryant 2017).

Relativist ontology and constructivist epistemology influenced the methodological possibilities, data collection and analysis and theory built up for this study (as described in Chapter 4). Consequently, pragmatism and symbolic interactionism principles (especially Blumer's) provided a relevant theoretical framework to

¹⁴ Immersion was done by various methods and techniques which will be described in Chapter 4.

¹⁵ As explained previously, being an informal carer myself, a nurse and my past experiences already make me somewhat familiar with the social processes of informal carer.

consider. Furthermore, these principles fit well with the current study's aim to create a theory about the social process of informal care during admission and hospitalisation, a theory of human behaviour and an inquiry about human conduct and group behaviour (Annells 1996). Using symbolic interactionism and pragmatism in conjunction with a relativist ontology and constructivist epistemology, I could combine 'theory and method into a coherent, unified whole without forcing the data and ideas into a prescribed set of concepts' (Charmaz 2014, p. 277). Constructivist grounded theory was chosen as the research study's methodology, since its roots stem from symbolic interactions, it adopts relativist ontology and constructivist epistemology, and it could answer the research questions presented in Chapter 2 (Aldiabat and Le Navenec 2011, Milliken and Schreiber 2012, Charmaz 2014).

3.3. Grounded theory

3.3.1 Rationale for grounded theory methodology

Grounded theory research aims to generate a theory that is grounded in the data based on a systematic and structured approach to gather, analyse, code, and conceptualise data on the research area being studied (Charmaz 2006, 2014, Birks and Mills 2015). Besides that, grounded theory is a methodology that sets out to construct a theory about a social process of importance in people's lives (Birks and Mills 2015). This is important as grounded theory aims to develop a theory that explains the social process being studied, rather than only reporting it, through abductive and inductive logic and reasoning (Charmaz 2009, Birks and Mills 2015). Therefore, grounded theory methodology was considered especially suitable for this research project because:

- *Little is known about the area of study.* Despite the importance of informal carers on the recovery of patients with CHF, few articles were identified in the initial literature search (Chapter 2) which focused on the informal carers of patients with CHF during admission and hospitalisation. No articles or studies were found that address the informal care of patients with CHF during admission and hospitalisation in Malta. Most of the articles addressed a clinical programme or a specific medical intervention, or focused on other diseases like cancer, stroke, or dementia care. Consequently, grounded theory is appropriate when little is known about the topic (as stated in Chapters 1 and 2). Due to its exploratory and

inductive style of inquiry, grounded theory is ideal for generating relevant and significant knowledge (Birks and Mills 2015).

- *Theory will be generated, with explanatory power as its desired outcome.* The ultimate aim of this research project is to construct a substantive theory¹⁶ that explains the social process of informal care during admission and hospitalisation. The substantive theory is grounded in data through interaction and co-construction of the participants' and researcher's real concerns, perceptions, and actions relative to this process, which is congruent with the presented philosophical stance in this chapter. Moreover, a theory offers an account of how the social process of informal care during admission and hospitalisation ensues and aims to account for why it happened (Charmaz 2014). Therefore, the theory consists of the actions involved in constructing the social process. Addressing the informal care during admission and hospitalisation raises questions about the meaning and moral value of the caregivers and patients involved (see Chapter 2). The substantive theory presented in this study aims to interpret and conceptualise the understanding rather than explain the social process involved in abstract terms (Charmaz 2014). In other words, a theory 'offers an imaginative theoretical interpretation that makes sense of the studied phenomena' (Charmaz 2014, p. 231). Finally, constructing a theory was deemed necessary because it answers the research question's interest in a social process developed from the initial literature search and my past experiences.
- *An inherent process is embedded in the research situation that is likely to be explicated by grounded theory methods.* This study sought a deeper understanding of the complex and often hidden factors surrounding the informal care of caregivers during admission and hospitalisation, which is not easily disclosable (Birks and Mills 2015). Furthermore, grounded theory methods allow the researcher to shift and capture the context, conditions and circumstances as things change and move on within the studied research area (Urquhart 2013). This is relevant because informal care is dynamic and unpredictable due to the chronicity and instability of

¹⁶ Substantive theory is defined as a theoretical interpretation or explanation with the boundaries of a clearly defined subject area (Charmaz 2014).

the patient with CHF, especially during the acute phases of admission and hospitalisation (Brannstrom et al. 2007, Luttik et al. 2007, Sandford et al. 2011, Yeh and Bull 2012, Lowson et al. 2013). Furthermore, hospital admission and hospitalisation are important processes for informal carers taking care of a patient with CHF, which could have a distressing effect on their psychological and physiological well-being (Levine 2002, Giles and Hall 2014).

This study's methodology, method, and output was a grounded theory approach. Further explanation will follow the specific grounded theory approach and methods used within the research design.

3.3.2 Approaches to grounded theory

Grounded theory was initially developed by two sociologists, Glaser and Strauss, when they published their seminal text titled *The Discovery of Grounded Theory* in 1967. The work of Glaser and Strauss explained a new approach to social research which sought to discover a theory grounded in and systematically derived from the data without prior assumptions or hypotheses (Charmaz 2014). This new and innovative research style involved generating a theory rather than verifying an existing theory (Stern 2009). Therefore, Glaser and Strauss (1967) presented a structured, robust, and credible research design using a logical deductive and inductive reasoning inquiry. Thus, the grounded theory approach provided researchers interested in human experiences and social processes with a practical method to systematically analyse data and generate a substantive theory.

The grounded theory evolved and developed in various approaches during the following years. Three of the resultant approaches are Classic or Glaserian grounded theory underpinned by positivism (Glaser 1978, 1992); Strauss and Corbin's pragmatic-symbolic interactionist approach to grounded theory (Strauss and Corbin 1990, 1998, Corbin and Strauss, 2008); and Charmaz's constructivist interpretive approach (Charmaz 2006, 2014). It is important to familiarise oneself with these three major schools of grounded theory in order to situate this research study in a position to address the research question and objectives. As a result, the Classic grounded theory with a positivist underpinning is not congruent with the philosophical underpinning (relativist ontology and constructivist epistemology) discussed in this chapter. However, in a careful analysis of classic

grounded theory texts, Gibson and Hartman (2014) conclude that there is no evidence to support the idea that it is based on positivism. Clearly this requires further analysis and debate, which is beyond the scope of this thesis. Nevertheless, having a detached researcher and having theory discovered from data rather than constructing the theory through an active and interactive process is inconsistent with the constructivist and relativist views presented in this chapter. However, reading about the classic grounded theory publications helped me to develop and expand my knowledge about grounded theory research. Strauss and Corbin's (1990, 1998) version of grounded theory seemed to be congruent with this research study's relativist, constructivist, and pragmatic-symbolic interactionist position. Strauss and Corbin's (1990, 1998) approach adopts strong pragmatist and symbolic interactionism views. However, as a researcher, I found Charmaz's constructivist interpretation of grounded theory to be the most congruent with my relativist ontological and constructivist epistemological positioning, and the most appropriate approach for addressing the research question (see Section 3.3.4 for further rationale and justification)

3.3.3 Characteristics and debates in grounded theory

Although the above subsection highlighted the differences in the philosophical positions adopted by different grounded theory approaches, there are essential elements held in common. These include memoing, theoretical sampling, comparative analysis and developing a theory (Charmaz 2014, Birks and Mills 2015, Kenny and Fourie 2015). Writing memos is the cornerstone and crucial method in grounded theory because it links data collecting, analysis, the researcher's thinking and thoughts, and writing the substantive theory (Charmaz 2014, Birks and Mills 2015, Kenny and Fourie 2015). Furthermore, memos help further concurrent data generation and analysis by constantly comparing data with data, codes with codes, codes with categories, and categories with other categories (Charmaz 2014, Birks and Mills 2015). This process and reflexivity eventually helped me to theoretical sample¹⁷ participants according to the data collected, analysed, and compared (Birks and Mills 2015). This research aimed

¹⁷ Theoretical sampling is defined as a type of grounded theory sampling in which the researcher aims to develop the properties of the developing categories or theories (Charmaz 2014).

to follow the above essential methods, as explained in greater detail in Chapter 4.

3.3.3.1 Literature review debates

Despite sharing the above essential characteristics, different grounded theory schools of thought have various points of divergence. The biggest point of divergence in grounded theory is using previous literature and conducting a literature review. Usage of literature at the initial stage is one of the most controversial debates in grounded theory (Charmaz 2015, Birks and Mills 2015). Glaser and Strauss (1967) and Glaser (1978) advocate delaying the literature review until after completing the data analysis. Delaying the literature review could encourage the researcher to articulate their ideas about the topic under examination (Charmaz 2014). This premise puts the researcher in a position of entering the field as a 'tabula rasa' – without any preconceived ideas and knowledge (Dey 1999). This stance derives from the positivist position of the classic grounded theory of removing the researcher from the research and not contaminating the natural emergence of theory from the data (Kenny and Fourie 2015). Various authors have challenged this notion of entering the research field as a tabula rasa and have differentiated between an empty head and an open mind (Dey 1999, Strauss and Corbin 1990). Rather than entering the field as an empty head, it is more appropriate to enter it as an open-minded researcher by acknowledging that previous exposure and knowledge could inevitably influence the research (Dey 1999, Strauss and Corbin 1990, Charmaz 2014). Dey (1999), Strauss and Corbin (1990) and Charmaz (2014) do not dispute the notion of doing an extensive literature review at the end of the study but argue that a researcher cannot erase previous knowledge, ideas, experiences, and perspectives on the subject under examination. Kenny and Fourie (2015) state that literature can be used at every stage in constructivist grounded theory. However, Charmaz (2014) meant to use literature as a valuable source of data and as a means of enhancing theoretical coding at a later stage of data collection and analysis, when a theory has been developed, or a core category has been identified, or as guided by the data. Furthermore, Charmaz (2014) envisages literature usage in every stage while writing and presenting a report, and not specifically during early data collection and analysis. Acknowledging the researchers' background and knowledge and bringing them to the data analysis is different from obtaining new knowledge by literature because it could force and contaminate the data rather

than constructing knowledge from the data, especially if the researcher is a novice.

This project required a preliminary literature review for research plan approval and the MPhil to PhD registration transfer document. Such a preliminary literature review can help orient the research to the study area without necessarily imposing the existing theories and knowledge (Urquhart 2013). Therefore, a non-committal initial literature review was done to meet the requirements of a research plan approval and a transfer document to place the present study in the context of related research work, identify the gaps in pre-existing knowledge, justify the research topic and sensitise myself to the area. Moreover, literature was consulted in order to learn from other researchers' experiences of using grounded theory. Not using literature extensively until the late stages helped me not to force the data under examination. For instance, literature concerning informal care described the burden of the caregiver as one of the main components (Iqbal et al. 2010, Patel et al. 2007, Yeh and Bull 2012, Hwang et al. 2011, Bahrami et al. 2014, Luttik et al. 2007), but from the data obtained the participants seemed not to perceive informal care as a burden but as their duty. Moreover, the central concept of vigilance in the substantive theory presented in this study was never found in the initial literature review. Furthermore, not using literature early saved substantial time by not studying the 'wrong' literature, which could have prevented me from seeing what the data tells me.

3.3.3.2 Theoretical sensitivity

The above exercise of conducting a non-committal initial literature review and my experiences as a researcher, an informal carer and a healthcare professional (as described in Chapter 1) enhanced my theoretical sensitivity. Theoretical sensitivity is another highly debatable topic in grounded theory literature, and it is highly linked to the literature review and the researcher's experience. Bryant and Charmaz (2007) define theoretical sensitivity as a problematic concept for the researcher doing grounded theory methodology and methods. Theoretical sensitivity is crucial in applying ground theory methods (Bryant and Charmaz 2007), but the problem is how the researcher could get it without 'contaminating' the data and theory. Glaser (1978) states that the first step in gaining theoretical sensitivity is to enter the research with few predetermined concepts and ideas and without a prior hypothesis. However, this could be problematic for a

researcher because it could lead inexperienced grounded theory users to adopt unrealistic ideas about their work (Kelle 2007).

Researchers bring into their research and studies sensitising possibilities from their training, reading, researcher experiences and explicit theories (Holton 2007). These might be useful compared to systematically gathered data, together with theories emerging from an analysis of these data (Holton 2007). Furthermore, Strauss and Corbin (1998) suggest that the inductive aspects of the grounded theory could have been overstated and present a theoretical sensitivity that acknowledges the importance of researchers taking into account their prior experiences and theoretical ideas. Glaser and Strauss (1967) locate theoretical sensitivity within the researcher in which abduction helps and enhances the researcher's intuition in understanding theorising. Theorising means stopping, pondering, and thinking afresh (Charmaz 2014). In this thesis, this was done very frequently by having an adequate time gap between one interview and another and between one group of interviews to another to stop and think afresh and inquire what the data is telling me (see Chapters 4 and 5). This was done to examine the flow of the examined social process of informal care by segmenting the data to create an explanation, organisation, and presentation rather than discovering order within the data (Charmaz 2014).

Moreover, to gain theoretical sensitivity, I had to look at the studied social process from multiple viewpoints, make comparisons, follow leads, and build on ideas. This was mainly done through diagramming, memo-writing, using gerunds, and frequent meetings with my PhD supervisors (see Chapter 4). Through this process, I could chart my direction through the acts of theorising and by adopting gerunds, especially in the early coding fostered by theoretical sensitivity (Charmaz 2014). /

3.3.3.3 Reflexivity

This confusion and debates within the grounded theory method can be a fruitful teaching moment for the researcher by using reflexivity in the research process. Reflexivity is another highly debatable topic in grounded theory (Mruck and Mey 2007). Glaser (2002) specifically rejected the notion of reflexivity during the research process, in which the use of reflection could lead to forcing the data, paralysing and hindering the process. Strauss and Corbin (1998) were more lenient in their approach and acknowledged the researchers' personal and

professional backgrounds as a critical aspect of the research process. The constructivist grounded theory approach highly recommends a reflexive stance to inform and conduct research, build rapport with the participants, and represent the participants and the researcher's voice in the written reports (Charmaz 2006). Since this research adopted a constructivist grounded theory approach, reflexivity was used during the initial stage of posing a research question and deciding the study's design, during sampling/data collection, during data analysis, and during writing and publishing. The next chapter will present a more in-depth explanation of how reflexivity was used in this thesis.

The above shows that literature review, theoretical sensitivity and reflexivity are connected, and their usage depends on the underpinning epistemological, ontological, and theoretical influences of the study. Nevertheless, the researcher's background and experiences affect the study's epistemology, ontology, and theoretical influences, shaping the research study. In order to avoid confusion, this study aims to represent transparently the decisions made by representing and questioning the underpinning epistemological assumptions, epistemological tensions, and ethical considerations (see Section 4.5). This shaped the relationships between what I see and what I know and how I went about designing and doing this research. This was done at each stage of this research, from design, concurrent data collection and analysis, through constant comparative analysis, to producing a theory grounded in data. The following section will discuss how constructivist grounded theory shaped my thesis and affected data collection and analysis.

3.3.4 Rationale for selecting constructivist grounded theory

Charmaz presented constructivist grounded theory as an alternative approach to classic grounded theory and Straussarian grounded theory (Charmaz 2006, 2014). Charmaz (2006, 2014) takes a middle ground between postmodernist and positivist stances by attempting to modernise (or post-modernise) the grounded theory method (Breckenridge 2012). Charmaz (2006, 2009, 2014) adopts different positions from classic objectivist grounded theory, which she defined as a clarification rather than a distinction from objectivist grounded theory. Indeed, Charmaz (2006, 2009, 2014) presented her version of grounded theory on the assumption of multiple realities, recognising the mutual creation of knowledge by the viewer and viewed, and aimed towards an interpretative understanding of

participants' meanings. Furthermore, Charmaz (2014) claims that constructivist grounded theory aims to build a theory that explains the social processes being studied from the viewpoint and consideration of the context of the participants, based upon a structured and systematic approach to the simultaneous gathering, analysing, and coding of data. Therefore, this study aims to generate a substantive theory about informal caregiving during admission and hospitalisation from the perspective of the informal carers taking care of patients with CHF in Malta.

Furthermore, constructivist grounded theory 'places priority on the studied phenomena and sees both data and analysis as created from shared experiences and relationships with participants and other sources of data' (Charmaz 2014, p. 239). Thus, relativism and reflexivity are pivotal to the constructivist grounded theory approach adopted for this study, enabling multiple perspectives of realities to be incorporated. Therefore, I was required to manage my values, beliefs, and assumptions by using reflexivity while acknowledging and interpreting the participants' thoughts and expressions.

Consequently, the use of constructivist grounded theory could address the research aim and objectives presented in Chapter 2 of this study. It allows for an exploration of the social process of informal care during admission and hospitalisation as held by the participants being interviewed. Also, constructivist grounded theory provided a platform for identifying and examining the social processes involved in the participants' main concerns and issues about informal care during admission and hospitalisation. Finally, this approach affected the design and implementation of the study. I sought to actively ensure that the methodology used reflected the ontological, epistemological, and theoretical positioning and drew on Charmaz's (2014, p. 15) constructivist grounded theory strategies listed below, which will be described and discussed in greater detail in Chapter 4:

- Conduct data collection and analysis simultaneously in an iterative process.
- Analyse actions and processes rather than themes and structure.
- Use comparative methods.
- Draw on data (e.g., narratives and descriptions) in service of developing new conceptual categories.

- Develop inductive abstract analytic categories through systematic data analysis.
- Emphasise theory construction rather than description or application of current theories.
- Engage in theoretical sampling.
- Search for variation in the studied categories or process.
- Pursue developing a category rather than covering a specific empirical topic.

3.4 Conclusion

This chapter presented the methodological explanation and justification of the research study, beginning with the researcher's philosophical positioning of a relativist ontology and constructivist epistemology. Then an exploration of the influencing roles of symbolic interactionism and pragmatism to this study was discussed. Constructivist grounded theory was justified as the most appropriate methodology to answer the research questions. The above strategies will be discussed further in the next chapter, when the methods used to operationalise the research methodology will be explained. Moreover, the research design, methods for sampling, data generation and analysis, and ethical considerations will follow, derived from the above stance and position. Furthermore, the next chapter will consider how methodological rigour was obtained, based on Lincoln and Guba's (1985) notion of trustworthiness (credibility, dependability, confirmability, and transferability) and Birks and Mills's (2015) determinants of quality grounded theory research (researcher expertise, methodological congruence, and procedural precision).

Chapter 4: Methods

4.1 Introduction

This chapter explores how constructivist grounded theory with a relativist ontology and a constructivist epistemology, together with symbolic interactionism and pragmatism as a theoretical framework, influenced the research design, sampling technique, data generation and data analysis. It also explores the adopted ethical considerations and measures to enhance methodological rigour. Ethical considerations include explaining how the researcher addressed ethics and governance, providing information about informed consent and keeping data safe and confidential to potential participants. Methodological rigour was achieved through trustworthiness, authenticity, and the following determinants of quality of grounded theory research: researcher expertise, methodological congruence, and procedural precision (Birks and Mills 2015, Lincoln, Lynham and Guba 2011). By explaining the research methods, this chapter demonstrates how constructivist grounded theory methods aligned with the research methodology presented in Chapter 3.

4.2 Research design

The research questions and aim presented in Chapter 2 were shaped by the initial literature review and my personal and professional experiences. They involved trying to co-construct the social process of informal care by caregivers during admission and hospitalisation of patients with chronic heart failure in Malta. The final aim of this study was to co-construct a substantive theory grounded in data that explained the social process of informal caring during admission and hospitalisation of a patient suffering from CHF in Malta. Consequently, a constructivist grounded theory with a relativist ontology, constructive epistemology, symbolic interactionism and pragmatic views was deemed fit to answer the research questions and address the aim of this study. The philosophical and theoretical perspectives affected the qualitative research design, which influenced the data collection and analysis process. The following section describes the overall strategy chosen to integrate the different components of this study logically and coherently by addressing the research questions and aim and abiding by Charmaz's grounded theory methods.

4.2.1 Sampling/Population

The participants were informal carers and their respective relatives suffering from CHF in Malta, who were recruited as in the below criteria.

4.2.1.1 Inclusion and exclusion criteria

The inclusion criteria were as follows:

- Informal carers were adults (18 years and over) who were informal caregivers of patients with CHF during hospitalisation in the last six months.
 - The intention was to interview informal carers who have been through admission and hospitalisation not more than six months before the interview. This aided with memory and recollection of the event. Informal carers were not interviewed during hospitalisation because admission and hospitalisation could adversely affect the psychological and physiological well-being of the informal carers (Levine 2002, Giles and Hall 2014), and adding more psychological and physiological stress to the participants goes against the ethical principles underpinning this study.
- Patients with CHF who have been discharged from hospital and had been living at home.
 - Patients were included in this study to have a more in-depth picture of what constitutes informal care from the patient's perspective and how they contribute to it. Although the research is about admission and hospitalisation, patients were not interviewed during hospitalisation because this could have induced excessive stress, which could hinder their recovery. Moreover, this study was conducted on the ethical principles of beneficence, whereas interviewing the participants during their acute phase could do more harm than good.
- Patients who had had one or more hospital admissions in the previous six months due to exacerbation of CHF or other CHF complications (patients with co-morbidities were included as long as one of the reasons for admission/readmission was attributed to CHF).

The exclusion criteria were as follows:

- Participants that have communication difficulties and therefore cannot participate in a conversational style interview.
- Participants who lack the capacity to consent.
- Participants who do not speak Maltese or English.

The above exclusion criteria were devised to identify the best possible participants for this research (Morse 2007). Having participants who could not communicate or speak in a language which the researcher can understand, interact in and interchange views in defies the importance of co-constructing knowledge between the researcher and the participants using the interview process. One could argue that the researcher could have employed a translator to include participants who could not speak Maltese or English. However, translations could alter the participants' meaning, contaminating the data, especially if the researcher is not proficient in the language.

The above criteria were intentionally broad with no distinction between gender, the type of relationship between the informal carer and the patient, or the number of admissions. As a grounded theory study, this allowed flexibility in participant recruitment and participation as the research progressed, all the while using the theoretical sensitivity to steer the purposive and theoretical sampling process. The scope of this grounded theory study was not to have a representative population of informal carers but to locate 'excellent' participants to obtain 'excellent' data to co-construct a theory about the social process under examination (Morse 2007).

4.2.1.2 Sampling and recruitment strategy

A credible, original, and useful theory could be obtained by having a recruitment strategy that reflected the study's research questions and aimed to examine the social process of informal care during admission and hospitalisation (Morse 2007, Charmaz 2014). Researchers must not only develop the theoretical concepts and their relationships to each other 'but also describe the actions, roles and interactions as they respond to and adapt within particular situations' (Morse 2007, p. 229). This could only be achieved by abiding by the tenets of the constructivist grounded theory methods. Therefore, having a recruitment strategy and sampling technique with the scope of locating 'excellent' participants and obtaining 'excellent' data to co-construct a substantive theory will be explained in more detail in this section (Morse 2007).

The participants were recruited using two main strategies: an advert in poster form, and using key people in the clinical area. Adverts in Maltese and English (see Appendix 1) were placed in prominent places in the hospital,¹⁸ including the main foyer, hospital car parks and the hospital cafeteria, in all the medical and cardiac wards and the outpatients' department. The posters were evaluated and approved by the College Research Ethics Committee for the College of Life, Health and Physical Science at the University of Brighton and the University Research Ethics Committee of the University of Malta. Although this strategy effectively reached a significant number of possible participants, it could not reach participants who have literacy problems and cannot effectively read and understand the posters. Another factor that was considered when advertising using a poster or any other recruitment strategy was the researcher safety issues, since the participants who responded were unknown to me. Given this, for every interview conducted, the lone-worker policy was evoked, as explained in Section 4.5.

The second recruitment strategy used involved the help of clinical staff on the medical and cardiac wards and in the heart failure clinic of the main general hospital in Malta. Through their experience and knowledge, they identified potential participants (informal carers and their respective relatives/patients) that met the inclusion criteria. The clinical staff outlined the purpose and nature of the study to the potential participants and how they could contact the researcher and opt into the study. During the recruitment phase, clinical staff were approached regularly to explain the study's changing nature and 'coached' to recruit participants who met the criteria listed above. It was made clear that participation in the study was voluntary, and no attempt was made to coerce people to participate. Participants opted in by emailing, messaging, or phoning the researcher to express their interest to be interviewed.

Nevertheless, using gatekeepers could result in bias as they may only choose participants who have a particular view, or could select patients they thought would put them in a good light. Other than that, the participants may feel constrained and forced to participate to accommodate the gatekeepers. Various methods were used to avoid coercion and biases during the recruitment phases,

¹⁸ As described in Chapter 1, in Malta there is one General Hospital.

as explained in the ethical issues section (see Section 4.5). However, using clinical staff as gatekeepers and recruitment champions was not as straightforward as it seemed to be at the start of the research study. Although most of the clinical staff were extremely helpful, the researcher had to convince them that the research was worthwhile and that facilitating the recruitment of participants could be beneficial. It was essential to consider that the clinical staff were extremely busy, and every time the researcher met them, he acknowledged and appreciated their input during this study. The researcher recognised that this recruitment strategy was extremely time-consuming but rewarding. Since a working relationship was built with the clinical staff, 'excellent' potential participants were successfully recruited.

Another type of recruitment that was unexpected and unplanned was the snowballing effect. Two participants recruited using the above strategies discussed this research with other people and friends. Those people discussed the study with their relatives and friends and expressed their wish to participate. This unexpected type of recruitment was discussed with the supervisors of this study, and the information sheet and informed consent as per ethical principles were abided by. It was decided to include them in the study and interview them. It is acknowledged that over-relying on the snowballing recruitment method could result in participants having similar views and failing to recruit a diverse sample (Morris 2015). Because of this, the snowballing method was kept to a minimum, and other recruitment methods were carried out as explained in the above paragraphs.

Locating an 'excellent' participant or informant that has been through the social process under investigation (in this case, the informal care during admission and hospitalisation) is crucial to obtain excellent data (Morse 2007). Therefore, this research study used the principles of sampling for grounded theory as outlined by Morse (2007, p. 235), starting with purposeful sampling and moving on to theoretical sampling.

Purposeful sampling is defined as recruiting participants who are in or going through the social process under investigation (Morse 2007). To have a rich description of the social process under investigation, the informal carers and patients with CHF were recruited according to the above criteria. A major critique of this method is that sampling can be subjective and biased (Morse 2007).

However, the scope of this sampling was not to generalise the data collected but to look for 'clues, sifting and sorting, and creating a plausible case' for participants who can contribute the most, thus providing rich data (Morse 2007, p. 238). The aim of this constructivist grounded theory study was to stay close to the data and not to seek the 'truth' but rather a conception of what was taking place in the social process of informal care during admission and hospitalisation of a patient with CHF (Savin-Baden and Major, 2013). As a result of the purposeful sample, seventeen people were recruited using the inclusion and exclusion criteria highlighted above. This initial purposive sampling provided a departure point, not theoretical elaboration and refinement (Charmaz 2014). Another method of recruitment in grounded theory could be convenient sampling, which should be used when there is a need to identify the social process and the boundaries and dimensions of the social process involved (Morse 2007). Convenient sampling was therefore not utilised because through the initial literature review and from my personal and professional experiences, I was sensitised to the informal care during admission and the hospitalisation social process. In view of this, the selection criteria were specific. They focused on a particular social process: participants who passed through the informal care of patients with CHF during admission and hospitalisation (see inclusion and exclusion criteria – Section 4.2.1.1).

The next sampling method was theoretical sampling, which arose from the data gathered alongside the concurrent analysis. As a researcher, I recognised what was important in the data and tried to acknowledge the data's meaning through memos and reflective diaries (Birks and Mills 2015). Memo-writing was the cornerstone not only for the grounded theory methods as a whole, but was also important to achieving theoretical sampling in a strategic, specific, and systematic way (Charmaz 2014). Memo-writing was done to augment abductive reasoning and discover variation (Charmaz 2014). This allowed the researcher to be theoretically sensitive and open to identifying what type of participants needed to be recruited or re-interviewed as the data emerged from the analyses of the interviews. For the purpose of this study, theoretical sampling is defined as a process of sampling data analysis and collection based on the emerging concepts in the data examined (Timonen et al. 2018). Dey (2007) states that theoretical sampling is a cornerstone of grounded theory; however, the practical aspect is problematic and limited. It is hard for a novice researcher to know when the

categories are sufficiently grounded and, therefore, identify when to stop producing and analysing data (theoretical sufficiency). Theoretical sampling was led by memo-writing and reflexivity. Thus, from the first five interviews (conducted between July 2016 to March 2017) conducted with ten participants, four participants were re-interviewed, based on the data analysed during that period (see Table 4). The below abstract from my reflective diary shows how it was planned to theoretically sample four participants due to the data analysed from the previous interviews:

During the initial data analysis of the data, I noticed that the participants have a lot of stress and fear during admission and hospitalisation. All ten participants described the discharge home as a blessing rather than being more stressful. I was surprised that all the participants did not fear going home, but their fear was when acute symptoms were present, and a hospital visit was necessary. The participants gave a lot of emphasis to the admission when in the acute phase of the patient with CHF. Participants expressed their feelings of anger, worry, fear and frustration during admission. During discharge, the participants expressed feelings of joy and re-union and returned to normality. Most participants took a lot of their interview time to discuss admission and hospitalisation, not the discharge process. When prompted by me to discuss the discharge process, all the participants went back to what happened during admission and hospitalisation. Therefore, what happens during admission and hospitalisation seems an important process relevant to the participants.

Now that I have identified the major concern of the participants (admission and hospitalisation), I need to re-interview participants from interviews 2 and 4 because they showed a lot of insight in the admission process and hospitalisation.

(Memo number 26112016)

Therefore, from the analysis of these first interviews, initial codes like loss of dignity, not being recognised, delaying of care and fear (see the memo in Appendix 3) were found predominating in all the interviews done when asked about their admission and hospitalisation. During these re-interviews, emphasis was given by the researcher to the process of informal caregiving during admission and hospitalisation. Four participants from the interviews conducted were re-interviewed because they showed more insight into informal caregiving during admission and hospitalisation than other participants. Another aim for this theoretical sampling by re-interviewing these four previous participants was to

develop a theory that emerges from the data. In fact, one carer was a healthcare professional, and the other carer had a long history of readmissions and hospitalisations during the years of informal caring for her husband. However, theoretical sampling was not yet complete at that stage, and further theoretical sampling occurred. The theoretical sampling was based upon the data analysis and direction from the first 11 interviews (see Section 4.4.2). Although concurrent data collection and analysis after the eleventh interview was incomplete, the emerging theory indicated that the main focus should be on the informal carers; it was decided to interview only the informal carers to illuminate and provide deeper insights into the phenomenon. The intention was to re-interview informal carers from the first 11 interviews/participants who were daughters and informal carers who were wives or husbands and compare how the relationship affects informal care during admission and hospitalisation. This is because, at that time, the importance of the relationship between the informal carers and their wife/husband/father/mother was emerging strongly in the data analysed, which suggested a further investigation into how the relationship between the informal carers and their relatives suffering from CHF during admission and hospitalisation was affected.

Furthermore, re-interviewing informal carers who had their relative admitted once during the last six months and other informal carers who had their relative admitted multiple times was done to compare how these continuous multiple admission events could have affected the informal care. This is because multiple admissions and hospitalisations could mean that the relatives of the informal carers were more unstable, and fear of death and separation could have been more evident than in relatives (patients) of informal carers who had had only one admission. At this stage, this theoretical sampling was considered a tool of theoretical exploration rather than theoretical confirmation or investigating cases.

After conducting the 12th interview, a re-interview with a previous participant, some of the patients/participants from the first interviews (interviews 1 to 11 – see Table 4) died. To avoid unnecessary distress to the informal carers whose relatives had died, it was decided not to re-interview the previous participants but to search for new participants and focus on daughters or wives and informal carers who had one admission and informal carers who had multiple admissions. Another four participants were identified (Danielle, Winter, Daphne and

Dominique). This was further done to respect the trust that the participants of the first 11 interviews had in me as a researcher. Re-interviewing them when their loved one had died felt like dehumanising and disrespecting the participants by giving more importance to the thesis rather than to the participants. Ignoring such reciprocities and respect could have weakened the chance of obtaining honest data and not being truthful to myself as not only a researcher but even as a healthcare worker and informal carer (Charmaz 2014).

The above sampling strategy aimed to obtain a rich, well-scoped grounded theory study by aiming at theoretical sufficiency (Morse 2007). Most grounded theory literature states that one should aim for theoretical saturation, but I recognise that obtaining theoretical saturation is complex and problematic (Charmaz 2014). Dey (2007) claims that theoretical saturation is unattainable. There are various reasons why theoretical saturation is unattainable; one of the biggest problems with the term saturation is the inconsistencies that exist in the literature on how saturation should be conceptualised and used (Saunders et al. 2018, Sebele-Mpofu 2020). In broad terms, saturation is defined as when the researcher hears or observes nothing new and therefore data collection is discontinued, focusing on data saturation rather than theoretical saturation (Stern 2007, Saunders et al. 2018). Specifically, in grounded theory literature, saturation is defined as when gathering new data reveals no new theoretical insights emerging or does not reveal new properties of the theoretical core categories where the focus is on the theory build-up rather than on data (Glaser and Strauss 1967). Therefore, sampling should determine further and adequate data collection based on the development of the theory (theoretical categories) in the analysis process (Saunders et al. 2018). Theoretical sampling and saturation are therefore closely related.

In contrast, sampling is guided by the emerging theory and combines sampling, data collection and data analysis instead of a separate linear process (Dey 1999, Bryman 2012). However, different grounded theory authors put different foci of saturation in the research process. Some authors relate saturation to the emergence of new codes or themes (Birks and Mills 2015, Olshansky 2015), while others relate it to the degree to which identified codes or themes are exemplified in the data (Starks and Trinidad 2007). This research study aimed not to give a clear definition of the concept of theoretical saturation but to

articulate the methodological strategies carried out by providing a thick description of the methods used, which are congruent with the philosophical positioning presented in the previous chapter.

Dey (1999) goes beyond the term saturation and views theoretical saturation as imprecise in grounded theory. Saturation is an ongoing and cumulative process that a researcher could never reach in a published report (Glaser and Strauss 1967). There is always a possibility to find additional properties or dimensions, and/or something new can emerge (Strauss and Corbin 1998). In view of this, this study aimed for theoretical sufficiency rather than theoretical saturation. This is because the established categories should be suggested by data instead of saturated by data (Dey 1999). This was not dependent on the sample size but rather on when the collected data showed no new categories, properties, or theoretical sufficiency (Charmaz 2014). Therefore, data were collected until the theoretical categories no longer demonstrated any new properties. There was enough, robust, and convincing data with adequate depth and scope to substantiate the theoretical categories found (Charmaz 2014). In view of this, data collection and generation continued until the point in time when the amount of data collected was considered suitable and sufficient for theoretical sufficiency (Charmaz 2014). It was done by drawing on my past personal and professional experiences, the initial literature review, and reading about and familiarising myself with the different grounded theory methodologies. Reflexivity helped me obtain the theoretical sufficiency of this study (Aldiabat and Le Navenec 2018). Furthermore, memoing and writing a reflective diary were guided by the following questions (Charmaz 2014, p. 33) to evaluate if the data (and memos) were sufficiently rich, substantial, and relevant to support the developed grounded theory (see Appendices 3, 4, 5, 6, 7, and 20):

- Have I collected enough background data about persons, processes, and settings to have ready recall and to understand and portray the full range of contexts of the study?
- Have I gained detailed descriptions of a range of participants' views and actions?
- Do the data reveal what lies beneath the surface?
- Are the data sufficient to reveal changes over time?
- Have I gained multiple views of the participants' range of actions?

- Have I gathered data that enable me to develop analytic categories?
- What kind of comparisons can I make between data? How do these comparisons generate and inform my ideas?

4.2.1.3 Participants

In total, twenty-one participants (thirteen informal carers and eight patients) were interviewed. All the purposively sampled participants participated in at least one interview. Eight informal carers and eight patients were interviewed together (see Section 4.3.4 for further rationale), whereas one informal carer was interviewed alone. However, after five interviews, theoretical sampling involved returning to four participants (two informal carers and two patients). Each of them appeared to have a deeper insight into the informal care during admission and hospitalisation (see Table 2). Each interview lasted between 45 and 60 minutes. All the participants indicated that they would be willing to have further follow-up interviews and be contacted in the future if needed. However, since some of the participants (patients) had died when contacted the second or third time, to avoid unnecessary upset, it was decided to recruit four more participants for the theoretical sampling (see Appendix 22 for more detailed information on the participants).

Table 4: Overall timetable of the interviews conducted in this study

Interview	Participants' Pseudonyms	1 st set of interview data (Purposively sampled)	2 nd set of interview data (Theoretically sampled)	3 rd set of interview data (Theoretically sampled)
1	Pamela Lee Harry Lee	15 th July 2016		
2 and 6	Patricia Bailey Darlene Bailey	2 nd August 2016	20 th March 2017	
3	Patrick Paps	18 th August 2016		

	Wendy Paps			
4 and 8	Philip Quin Whitney Quin	30 th August 2016	18 th April 2017	
5	Peter Zane Winnie Zane	8 th March 2017		
7 and 12	Paula Galle Daryl Galle	29 th March 2017		1 st May 2018 (carer only)
9	Pia Hale Hamilton Hale	10 th April 2017		
10	Dawn Mason	29 th April 2017 (carer only)		
11	Pam Miles Harley Miles	10 th May 2017		
13	Danielle Lancaster			3 rd May 2018 (carer only)
14	Winter Lancaster			5 th May 2018 (carer only)
15	Daphne Martins Dominique Martins			26 th May 2018 (carers only)

During the recruitment phase, more participants (four patients and four informal carers) showed interest in participating in this study, and they opted in by phoning or emailing me. However, during the subsequent meetings to clarify and confirm their participation, they refused to sign the informed consent and participate in

this study. The participants' refusal could be explained by the fact that when the gatekeepers presented this study to them, in order not to go against their healthcare professional's perceived wish (unintentional) they accepted in the first instance. However, the ethical principles highlighted in Section 4.5 were implemented to protect the participants from coercion. This highlighted the importance of abiding by the ethical principles to minimise the possibility of harm to the participant. Furthermore, three patients died after recruitment and before the interview could take place. The informal carers of these patients were not interviewed (although some of them offered to conduct the interview) out of respect and/or to avoid unnecessary harm. Furthermore, in Interview 10, one can notice that the interview was done only with Dawn, the informal carer. This was because her mother was sleeping at the time of the interview, so for practical reasons it was decided to interview Dawn alone. Rescheduling the interview with Dawn's mother was not done because the data and interview (Interview 10) indicated that interviewing informal carers alone might give more insight into the social process under examination.

4.3 Data generation

4.3.1 In-depth interviews

Informal carers and patients with CHF were invited to participate in conversational style semi-structured audio-recorded interviews that were then directly transcribed by the researcher. In-depth conversational style interviews were congruent with the constructivist grounded theory approach, which seeks to explore how participants construct the topic under investigation by exploring the participants' experiences and situations (Charmaz 2014).

Carter and Little (2007) and Charmaz (2015) argue that the researcher's epistemological and ontological stances should shape the method. The methods that the researcher chooses and how these methods are used flow from these positions (Carter and Little 2007, Charmaz 2009, 2014, 2015). Therefore, the in-depth interviews were chosen for data collection because, as a researcher, I acknowledged that I could not separate myself and my experiences from the research or be entirely objective about the data. Furthermore, I sought to co-construct the data through interaction between the researcher and the participants. This was achieved through reflexivity and relationality throughout the whole process, which eventually enhanced this study's rigour (see Section 4.6).

However, one of the major critiques of in-depth interviews is that conducting an in-depth interview as a method of collecting data provokes participants' responses to preconceived questions (Charmaz 2015). This eventually could generate the researcher's accounts, justifications, and performance rather than the participants' (Rapley 2001, Silverman 2007). However, data can be co-constructed by in-depth interviews just as with any other data collection method (such as observation, focus group or Delphi technique) (Charmaz 2015). Co-construction of data is more evident in in-depth interviews than in any other data collection method and thus provokes criticism regarding the objectivity, truthfulness or quality of the data collected (Charmaz 2015). This is because 'interviewing provokes taken-for-granted metaphors, produces unexamined interview questions, creates collusion between the interviewer and the research participants, results in inaccurate participants' accounts and leads to questionable research reports' (Charmaz 2015, p. 1613, Alvesion 2011, Miczo 2003, Potter and Hepburn 2012, Silverman 2007).

The following strategies were utilised to address the above criticism, and justifications will be highlighted. To conform with the philosophical stances highlighted in the previous chapter, the in-depth interviews allowed the participants and the interviewer to co-construct knowledge between themselves by using interviews as a means of data collection. Interviews are an interchange of views and ideas between two persons conversing about a theme of mutual interest (Kvale and Brinkmann 2015). This conforms to the relativist ontology and constructivist epistemology of this study (Kvale and Brinkmann 2015). Therefore, these in-depth interviews provided the participants' discussion and interpretation together with the researcher's analysis and interpretation of informal care during admission and hospitalisation by asking open-ended, non-judgemental questions using an interview guide (see Section 4.3.3 and Appendix 16, 17, 18, and 19).

Another justification for using in-depth interviews was that they provided the opportunity to combine the flexibility and control of interviewing by being open to the interactional space for ideas as issues arose, which no other method could provide (Charmaz 2014). Furthermore, interviewing the participants allowed for the immediate follow-up of some ideas and topics (Charmaz 2014). This resulted in social interaction between the researcher and the participants, which conforms

to the epistemological and ontological stances of this study and combines the simultaneous data collection and analysis of grounded theory (Charmaz 2014).

Another justification for using interviews as a method of data collection was that they allowed the researcher to go beneath the surface of the described experiences of the participants, by asking the participants to explain in more depth their thoughts, feelings and actions about their experience during admission and hospitalisation concerning informal care in which intensive interviews are ideal (Charmaz 2006, 2014). Restating the participants' points, slowing or quickening the pace, shifting the immediate topic and going back to an earlier point during the interviews helped the researcher keep the participants focused on the subject (Charmaz 2006, 2014). During the interviews, emphasis was given to the participants' views and/or stories, and the researcher expressed appreciation by validating the participants' perspectives or actions. This was done mainly by restating the participants' points, giving them time to express themselves, giving them space to communicate, doing the interview in a quiet environment free from interruptions, and dedicating enough time for the interview.

Furthermore, during the interviews, it was possible to use observational and social skills, and especially to pick up on the subtle non-verbal cues to enhance the discussion (Charmaz 2006, 2014). This was done by observing the non-verbal cues, which included awareness of the facial and bodily expressions of the participants, such as happiness, sadness, anger and fear. All the participants exhibited some form of expression during the interviews, e.g., some participants had facial expressions of anger and sadness when discussing that their relatives were not treated with respect during hospitalisation. On noticing their facial expression, the researcher tried to probe into that episode by asking them to clarify and express those feelings verbally. Another form of non-verbal cue that was noted in the interviews was eye contact; when questions were asked about issues sensitive for the participants, like death or their future, most of the participants would break eye contact with the researcher, and some of them remained silent. For example, when a particular participant (informal carer) was asked directly about his future with his wife, he remained silent. Still, his facial expression showed sadness, and his gaze was lowered to the floor, suggesting to the researcher that the participant was anxious and worried. That particular

moment made the researcher reflect that the participant did not see a future with his wife due to her chronic illness.

This in-depth interview method was demanding because the researcher needed to remain 'attuned to what each participant is saying and doing, be theoretically sensitive to what this means for the developing theory and directing or following the interview accordingly' (Birks and Mills 2015, p. 73). Although the method was aimed at bringing the researcher's knowledge and experience into the interviews, he needed to be reflexive and self-aware to prevent any ideas, views, and knowledge from excessively influencing or forcing the process of data collection and analysis (Charmaz 2014, Gentles et al. 2014). Reflexivity was used throughout the study, including in the planning phase, while collecting and analysing data, and when memoing, and is further explained in Section 4.6.2.1.

4.3.2 Preparing for the interviews

Charmaz emphasises that the researcher needs to be knowledgeable and prepared in the skills of intense interviewing by preparing for the interviews (Charmaz 2011, 2015). Therefore, a few strategies were adopted to test and hone my interviewing skills and techniques. The scope of the exercises detailed below was not to collect data but to develop interviewing skills by constructive feedback, advice and reflexivity. Although I had experience interviewing participants for research purposes and postgraduate courses on research, in-depth interviewing using a constructivist grounded theory mindset was new. Assuming that my existing skills were enough to achieve the aims of interviewing in grounded theory research was a cardinal error that I wanted to avoid. The first strategy suggested by Janesick (1998) was to interview someone I know. Therefore, I interviewed a friend of mine (the interview was not related to the subject). On reflecting, I noticed that my approach to the interview was not structured, and time was lost looking around for pieces of paper or pen. Furthermore, I noted that I needed to be prepared with all the necessary items at hand (information sheets, informed consent form, interview schedule, laptop, audio recorder). From the feedback received from my friend, I noticed the importance of a quiet, private setting that was free from visual and auditory distractions. In view of this, an interview preparation checklist was developed, as described in Table 5.

Table 5: Interview preparation checklist

Before the interview:
Prepare a folder with the information sheets, informed consent forms and interview agenda.
Choose a physical setting that is quiet, private and free from visual distractions.
Ensure that clothing and personal appearance give a professional look.
Two digital audio recorders with spare batteries – check if it is working.
Inform colleagues and supervisors about the time and location of the interview.
Bring laptop with electrical cord to run on electricity during the interview.
Bring paper notebooks and pen (with spares) for note-taking and memoing.
Ensure that my mobile is switched off or on silent.
Print out interview agenda and keep it on the table above notebook for easy viewing.
On commencement of the interview:
Participant information letter – re-read together with participant, including the purpose of the interview, the selection procedure, what is expected, confidentiality, freedom to withdraw at any time, the right to refuse to answer, and the usage of the audio recorder.
Gauge capacity to consent by asking questions about the study.
Obtain signed and completed participant consent form.
At the conclusion of the interview:
Ask the participants if they are willing, if required, to be interviewed again at a later stage of the research.
Read the field notes and thoughts taken during the interview.
Write a reflective account of the interview.

The above interview preparation checklist ensured that I was fully prepared for each interview and had appropriate resources, equipment and time for data collection and analysis for each interview. Furthermore, I reflected that there was no actual process during the interview but just questions and answers in a clinical interrogation style. This was more evident when conducting the second exercise, in which Janesick (1998) suggested interviewing a stranger. As a clinician, I was used to interviewing people I was unfamiliar with every day for clinical purposes.¹⁹ On reflecting on those interactions, I noticed that I used an interrogation style rather than a conversational style. This derives from the premise that I lead the interview as a clinical person to obtain the information that I need, rather than co-constructing knowledge. In other words, I was acting as a clinician rather than a researcher. This made me aware of the unequal power relations inherent in the researcher-participant interactions. Therefore, various strategies were adopted to minimise this impact (see Section 4.5). To avoid these pitfalls in the interviews, an interview process was adapted after the literature was consulted, as can be seen in Table 6.

Table 6: Interview process, adapted from Janesick (1998), Charmaz (2014) and Morris (2015)

<ul style="list-style-type: none"> • Preparing 	<ul style="list-style-type: none"> • Introductions and thank-you • Time for establishing rapport between researcher and participant <ul style="list-style-type: none"> • Trial of voice-recording apparatus • Review study details and regain consent <ul style="list-style-type: none"> • Confirm interview process • Clarify expectations and interview ground rules for both participant and researcher
<ul style="list-style-type: none"> • Opening 	<ul style="list-style-type: none"> • Background information • Initial open-ended questions to introduce the subject and encourage participants to bring up issues most relevant to them

¹⁹ I did not interview a patient for the purpose of this study at this stage but reflected on my past experiences.

<ul style="list-style-type: none"> • Questioning and guiding 	<ul style="list-style-type: none"> • Intermediate questions • Ending questions • Exploratory probes – use throughout to draw out depth and information about social processes • Cooling-down prompts – use 15 minutes before the end of the interview
<ul style="list-style-type: none"> • Closing 	<ul style="list-style-type: none"> • End interview by asking participants if there is anything else they would like to discuss • Thank participant for the interview • Clarify details about the interview and whether further follow-up may be needed
<ul style="list-style-type: none"> • Post-interview 	<ul style="list-style-type: none"> • Reflect on interview content and process • Conduct initial review of data collected and analysed during the interview • Memo key ideas and analyse while the interview is still fresh in the researcher's mind • Refine interview questions for the following interview <ul style="list-style-type: none"> • Consider theoretical sampling

The above table reminded me that I needed to be a researcher and not a clinician before each interview. This reflective exercise continued throughout the data collection period and was conducted after each interview which helped in refining the interviewing technique and skills, as can be seen in the reflective memo below:

I felt that this interview went better than the previous one. The participants opened up more to the questions by giving a more in-depth account. I used and took notice more of the facial expressions and body language. I was clearer at the start of the interview and focused more on the informal carer issues. I had noticed that when the recorder went off, the relative relaxed, and after some time of talking, she opened up more, and some issues were mentioned (which were not included in the interview). Maybe, this shows that I am not spending enough time in the beginning to break the ice and make the participants more comfortable to build rapport. In fact, on listening again to the audio file, I have noticed that the participants were somewhat reluctant to talk openly at the beginning but talked more freely during the rest of the interview.

Plan for the following interview – take some more time to break the ice, ask about the area, ask about a particularly interesting object in the house, talk about current news.

(Memo number 10082016)

Resources and aids are important tools for an efficient and effective research study (Birks and Mills 2015). However, Glaser (1998) is strongly opposed to taping the interviews in grounded theory research because taping the interviews is inefficient, detracts from the focus of early category delimitation and generates mounds of superficial data. Taping the interviews and transcribing them could hinder the skill development of theory build-up (Glaser 1998). However, since the researcher was a novice to grounded theory research, the interviews were taped and transcribed. Tape recordings allowed the interview discussion to be unobtrusive, without disruption from a frantically scribbling researcher, thus allowing the researcher to concentrate on the participants' co-construction of the social process involved (Kvale and Brinkmann 2015). This helped the researcher re-listen to the interviews repeatedly and immerse himself in the data, especially at the beginning of the coding, and to re-check the initial codes (Birks and Mills 2015). Transcribing was done by the researcher; although it was laborious and time-consuming (a one-hour interview took the researcher between four and five hours of transcription), it helped the researcher further immerse himself in the data.

Furthermore, it is quicker and more accurate to find information in a transcribed interview than by repeatedly listening to the recording (Rubin and Rubin 2012). Although transcribing by someone else (such as administrative or clerical staff) could have saved a lot of time for the researcher, it was decided not to do that because others may not be trained to deal with the sensitive issues they may encounter while listening to the tape, and/or not be familiar with the medical terms, and a misinterpretation could occur. Furthermore, transcribing the interviews allowed the researcher to learn more about his interview style, and the analysis of the data could start at that point (Kvale and Brinkmann 2015).

The researcher took personal responsibility for arranging the following resources needed for this study:

- Digital voice recorder for recording interviews and a backup digital voice recorder in case the first one has a technical failure.

- Spare batteries for the digital voice recorders.
- Laptop with password protection and firewall.
- Password-protected USB stick for storing all confidential data.
- Lockable cabinet at home and work/study settings to keep a laptop, USB sticks, and digital voice recorder locked when not in use.
- Lockable briefcase to carry laptop, USB stick, and digital voice recorder while travelling between home and work/study settings.
- In the event of personal laptop and voice recorder failure, the researcher was ready to replace them.
- Paper notebooks for taking notes during interviews and memoing when a laptop was unavailable (notes and memos were then typed and saved electronically).
- Room to conduct interviews (the researcher had the option of a room in the hospital or University of Malta premises or participants' home. If the participants chose to interview in their respective homes, the Lone Worker Policy was evoked as explained in Section 4.5).

4.3.3 Setting up the interview guide

Developing and designing an interview guide helps satisfy the institutional ethical review committees. It also teaches the researcher to ask open-ended questions to elicit thoughtful answers about the participants' experiences (Charmaz 2014, 2015). The semi-structured interview questions were developed and co-constructed based on feedback and suggestions given by PhD supervisors, healthcare professionals, patients with CHF and informal carers.²⁰ By co-constructing it, this interview guide helped me better grasp how and when to ask questions in a conversation and eventually helped conduct the actual interview (Charmaz 2014). However, Rubin and Rubin (2005) suggest that an iterative design should be used, whereby the researcher uses an unstructured interviewing method with only a list of topics to cover during the course of conversation, or one general open-ended initial question. However, for a novice researcher, starting new research without a working guide could lead to pitfalls like asking awkward, poorly timed, and intrusive questions, leading to the

²⁰ Participants involved in the construction of the semi-structured questions were excluded from the actual research study.

researcher's unexamined preconception (Charmaz 2014). As a researcher of this study, I chose to develop a semi-structured interview guide to avoid the pitfalls described above, but keeping in mind the premises described below.

In view of the relativist ontology and constructivist epistemology, the interview guides were used as initial frameworks for opening the interview conversation rather than as recipes to follow (Charmaz 2015). This was done to enhance the participants' multiple views and co-construction of the data between the researcher and the participants. It was noted that sometimes the most important question that evoked many emotions in the participants was not in the interview guides (e.g., death and future). However, constructing and studying the interview guide helped me be more sensitised to the questions' content, pacing, intensity, and potential intrusiveness (Charmaz 2014, 2015). Because of this, I became aware of more of my taken-for-granted standpoints²¹ on the topic, embedded power issues, ethical issues, and hidden assumptions (Charmaz 2015).

During the development and co-construction of the interview guide, I tried to avoid any unexamined professional terms that can confuse or offend the participants, like using the word burdening instead of supportive. I purposely included introductory and concluding paragraphs to begin, frame and end the interview, tried to start with an initial background question, tried to avoid loaded or closed-ended questions, too many questions, and having a set sequence to the questions (Charmaz 2014). I reminded myself that this interview guide was only a guide, and I needed to return to the conversational level when interviewing the participants. However, the interview guide helped me refocus the participants from discussing issues that are not relevant to the study by bringing them back to talking about their role during admission and hospitalisation. On the other hand, as a researcher, I had to keep in mind that the interview guide would evolve and change according to the data emerging from the interviews. The interviews started with a very open question about the participants' experience during hospitalisation, aiming to probe the change in roles, participation, decision-making, and burden. The topic guide (see Appendices 16, 17, 18, and 19) was used to structure the conversation around topics that may emerge. The areas for discussion were an outline, and interviewees were encouraged to identify their

²¹ A methodological diary and a reflective diary were used.

concerns. As interviews and analysis progressed, the topic guide was altered to include emerging themes and issues (Charmaz 2006, 2014) This was evident in this study. The interview questions and conversations with participants evolved from burdening, role-changing, and decision-making topics guided by the initial literature review to other completely different codes and categories (vigilance, relationship, resilience - see Chapters 5 and 6). Therefore, the concurrent data collection and analysis was guided by the emerging theory and questions were asked according to the emerging codes. Furthermore, on reflecting, the interview guides were used less and less by the researcher as the study progressed. This is congruent with what Charmaz (2014) claims that a constructivist grounded theory researcher should create and search the concepts of what the participants are trying to tell us in a particular situation.

4.3.4 Dyadic interviewing

The grounded theory, an inductive research methodology for generating a theory, could use a combination of methods (Glaser and Strauss, 1967, Charmaz 2014). Methods for data collection in interviews can vary between internet-based, telephone-based, video-based, one-to-one, or focus group interviews (Hernandez 2011). Furthermore, Glaser (1998) stated and repeatedly emphasised that “all is data”, and various types of interviews are among the options that the grounded theory researcher has for data collection. However, one must always keep in mind that the methods chosen must always reflect and derive from the ontological and epistemological stances of the study (Charmaz 2015). As explained in the above sections, interviews were chosen because they reflect and justify the views of this study. The type of interviews conducted by this study will be explained and justified in this section.

For this study, the participants were given a choice to be interviewed either separately or together (patient and informal carer). From the fifteen interviews conducted, eleven interviews were conducted with two participants (ten with a patient and an informal carer, one interview with two informal carers) and the researcher. In contrast, four interviews were conducted with only the informal carer (one due to practicality and the other three due to theoretical sampling). The type of interview that has two participants apart from the researcher could be described as dyadic in nature. Dyadic interviewing was represented by Morgan et al. (2013, 2016) as a means to make two participants together with the

researcher interact between themselves by comparing, completing, or clarifying each other's statements. In a dyadic interview, the researcher takes the role of a moderator (Morgan et al. 2013); however, in this case the researcher's active role was required to abide by the constructivist grounded theory's methodology (Charmaz 2014). The researcher was more involved in the interviews than being only a moderator by being an active participant in the concurrent data collection and analysis, which occurred even during the interviews themselves.

The sharing and interaction mainly between the participants – informal carer and patient – and to an extent, even the researcher, allowed the participants to extend what the other had said while comparing to each other. This involved a process of differentiation that moved the discussion in alternative directions. In an interview, sharing ideas and interaction is congruent with the constructivist grounded theory of co-construction and multiple realities (the researcher, informal carer, and patients). Furthermore, the process of sharing and comparing in this type of dyadic interview by hearing interesting similarities and differences in what the participants think about the research topic was congruent with the grounded theory method of simultaneous collection and analysis and continuous comparison.

Dyadic interviewing differs from a focus group because dyadic interviews focus on the conversation between two persons rather than group discussion that occurs in a focus group (Morgan et al. 2013, Morgan 2016). Furthermore, dyadic interviews are more intimate than focus groups, with a closer relationship between the participants (Morgan 2016). In this research study, the two participants (informal carer and patient with CHF) were closely related. At the same time, the researcher tried to enter into this relationship by building rapport, being respectful, and acknowledging the participants' voices.

These types of interviews were chosen for various reasons. From experience, informal carers and patients complement each other and are dependent on each other. On the other hand, one could argue that the patient and/or the informal carer may be reluctant to express thoughts or feelings with the other party present. But through clinical experience, the researcher had noticed that when patients with CHF were asked for an opinion or to make an important decision, the patients usually sought the opinion of their respective informal carer and vice versa. By adopting this type of interview, the researcher tried to mimic and reflect

the natural setting of the informal care, which was that of being together and taking decisions together. Interviewing the informal carers and patients helped gain a deeper understanding by allowing deeper probing (Morgan et al. 2013, 2016). To further confirm this and be careful not to impose, a choice was given to the participants to be interviewed together or alone, and all the participants chose to be interviewed together.

However, interviewing the participants together could be a limitation as well as a strength (Kaasalainen et al. 2013). During the interviews, one participant could be more dominant than the other. This was noted in some interviews where the voice of some participants (in some cases the patient and in other instances the informal carer) was lost. Still, to avoid this, the researcher tried to involve the participants who appeared to speak less by probing, asking for their opinion, clarifying, shifting the discussion, and repeating the other participants' statements. Another alternative was to re-interview the participants whose voice was lost; however, the researcher did not deem it necessary.

Furthermore, interviewing both participants together was chosen because it reflected the constructivist grounded theory stances for practical and safety reasons. This type of interview was chosen because it is also congruent with the ontological, epistemological, and theoretical perspectives presented in the methodology chapter. For example, the advantages of dyadic interviews are that they provide an easily accessible opportunity to share experiences and reflection, create a level of comfort and openness, produce data at an in-depth level, generate a conversation that covers a wide variety of topics, and therefore co-construct a joint narrative of the social process involved. (Morgan et al. 2013, 2016, Morgan 2016). Practically, interviewing both patient and informal carer together saved a lot of time for the researcher and the participants. Doing a one-hour interview together was much more convenient and practical than doing two individual and separate interviews. The reason was greater ease of scheduling one interview with both the participants who lived together (or close to each other) at a time convenient for them, rather than scheduling two different interviews at a different time and/or day.

Moreover, this choice of being interviewed together was given for safety reasons. From the researcher's clinical experience, the patient and informal carer felt safer when a stranger interviewed/examined them with someone they knew. When

given a choice to be interviewed, alone or together, all participants chose to be interviewed together. For the researcher, it was safer to have two persons when going interviewing in an unknown place, especially if there was a fragile older participant. To safeguard the participants' vulnerability, various steps were taken during the study: obtaining informed consent, information giving, the right not to answer questions, the right to withdraw, and the right to have access to assistance if the interviews were harmful in any way to the patients. Further discussion and detail on ethical issues can be found in Section 4.5.

Furthermore, dyadic interviewing is ideal when a sensitive topic is difficult to explore by conventional methods (Morgan 2016). Admission and hospitalisation can cause distress for both the patient and the informal carer (Levine 2002). Moreover, having a trusted person in the interview who shared the same experiences makes the participants feel safer when disclosing sensitive topics (Morgan 2016). During the interviews, the researcher noted that the participants often supplemented each other by adding details, and sometimes even reminded each other about omitted episodes or details. The participants sometimes helped each other to express incomplete thoughts. Furthermore, in most of the interviews, the participants asked questions to clarify some points. This interaction and sharing of ideas helped obtain rich data and contributed to co-constructing the reality under examination (Morgan et al. 2013, Morgan 2016). In the interviews, it was noted that participants created a more complex account and sometimes provided alternative versions or realities of the phenomena under examination. This again conformed to the ontological and epistemological views of this study.

4.3.5 Language and interviews and their effects on coding and theory build-up

The participants were given the choice of conducting the interviews in their preferred language (Maltese or English). This preference was given to the participants because language is central and pivotal to grounded theory to fully express themselves (Tarozzi 2011, Charmaz 2014). Malta is a bilingual country, with both English and Maltese as official languages. Furthermore, the Maltese education system is based on English, with most textbooks written in English and examinations of most subjects taken in English. During the researcher's everyday interaction with people, he uses mainly the Maltese language, but for working,

writing and studying purposes, he uses the English language. Malta is an island in the middle of the Mediterranean Sea, but its healthcare system, educational system and culture are heavily influenced by the British culture due to the close history of both countries.²² Although the participants all preferred to conduct the interviews in Maltese, it came natural and easy for the researcher to think in English, even during the interviews. Furthermore, to analyse a Maltese transcript using English coding, it was essential to be familiar with both languages and know the topic in question (Tarozzi 2011). In this case, having experience as a nurse, as an informal carer, and conducting a non-committal initial literature review helped the researcher be more sensitive and understanding, and accurately translate and interpret what the participants were trying to say.

The transcription of the interviews was done in Maltese, but the initial codes, focused codes, memos and theory build-up were written in English. This was done because, in Maltese, there are no formal gerunds. In contrast, gerunds are used in grounded theory studies to encourage the researcher to elevate the initial codes to an advanced analytic level by combining them in the analysis and the emerging theory's build-up (Glaser 1978, Charmaz 2015). Additionally, thinking and writing in English from the beginning made it easier for a theory to emerge in the English language. However, conducting research in another language, not English, could be a powerful analytic resource (Tarozzi 2011). The researcher needed to read the text carefully and try to analyse, interpret and elaborate what the participants were trying to say and then code and write in English rather than translate.

Furthermore, this was congruent with grounded theory's constant comparative method. Another justification for using English in coding and memoing was that English being used frequently by the researcher could be more conceptualising and have greater propositional power (Tarozzi 2011). Therefore, English seemed more suitable in this study for making propositional statements, binding concepts, and expressing complex and tricky categories with synthetic nomenclature. English is familiar to the researcher, a synthetic language that condenses meaning into fewer words, perfect for creating titles, slogans, and categories.

²² Malta was a British colony for 174 years.

Furthermore, the target audience for this thesis are English-speaking, and no journal will accept articles written in the Maltese language.

However, coding in English of transcripts of interviews conducted in Maltese slowed the pace of the analysis, especially in the initial phases of coding, because sometimes the researcher struggled to find the word which summarised what it is being expressed in the Maltese data. The researcher found a thesaurus during coding and discussion with the supervisors very helpful in this process. Only the quotes in the findings chapter used to construct the theory were translated into English.

Another problem encountered during this phase was translating Maltese idioms and phrases that are difficult to translate in English. The language-culture link had to be considered; therefore, the researcher's knowledge of the participants' culture was necessary (Tarozzi 2011). Besides, having three PhD supervisors (one Maltese and two from the UK) was very helpful in having an alternative view of what the participants were trying to say. This knowledge of the language and cultural differences eventually helped further analyse the interviews by the researcher. For example, a participant described his wife as '*l-għoqda tiegħi*', which in English means 'my knot', which might not make much sense. However, the participant meant that his wife makes him strong like a knot and can also have the even stronger meaning that she completes him. In fact, on asking him to explain what he meant by '*l-għoqda tiegħi*,' he continued to explain that his wife is his life. Therefore, where possible, the quotes were translated to reflect the true meaning of the data. The quotes were translated with the help of the local supervisor. However, when an idiom or phrase could not be translated to English, the phrase was presented in Maltese, and an explanation in English was given. The researcher recognises that by using Maltese, another researcher with a different or the same background, knowledge and experience could interpret, analyse and construct a somewhat different theory from the same data obtained from this study, mainly because no two experiences are the same.

4.4 Data analysis

4.4.1 Simultaneous data collection and analysis

Simultaneous data collection and analysis is one of the main strategies in grounded theory research (Birks and Mills 2015, Timonen et al. 2018). However,

this does not necessarily mean that the researcher must conduct a thorough analysis after each interview. Still, a quick and superficial analysis was performed after each interview before going for another interview. Birks and Mills (2015) clearly state that analysis could be started after the researcher collects data from an initial purposive sample to grasp what was being said before embarking on coding and analysis. Furthermore, Timonen et al. (2018) go beyond that and state that, although ideally the researcher should immediately embark on data collection and analysis, it is not always practical. It depends on the time frame, sample size, the scope of the study and the topic at hand (Timonen et al. 2018). For this research study, the researcher recognised and maintained as much as possible the method of simultaneous data analysis and data collection (Charmaz 2014). However, one of the main problems that the researcher encountered during the recruitment phase and therefore during maintaining the concept of simultaneous data analysis and data collection was that some participants were too sick and died before the interview could happen. Thus, the researcher took every opportunity when a participant was identified and accepted to interview them as soon as possible. Furthermore, the researcher tried to accommodate the participants' time window to participate in this study. Sometimes, this happened quickly after another interview, with little time to analyse the data of the last interview.

Constant comparison was maintained during the data analysis and even during data collection (the interviews). An interview guide was used (see Appendices 16, 17, 18, and 19); it was designed to facilitate a co-constructing of meaning and was used as a guideline to open discussion. Eventually, discussions during the interview evolved according to the participants' views and construction of the informal care during admission and hospitalisation. In due course, questions were changed according to what the participants said and discussed. Moreover, during the interviews, the researcher compared what the participants were saying with the data from the previous interviews.

Additionally, during the interviews, due to the nature of dyadic interviewing, a constant comparison between the patients and the informal carers was made by rephrasing, summarising, and clarifying their statements (Morgan 2016). In the case of an interview being conducted soon after another interview, the researcher did a rapid, brief analysis, which he would use in the following interview, with the

intention to analyse comprehensively, code and compare the interview at a later stage. The researcher transcribed the interviews, which allowed him to become fully immersed within the data, and initial codes were given to the data gathered.

The constant comparative methods adopted in this study highlights the fact that co-construction of the new substantive theory was done mainly with interaction with data rather with the participants. This was done to go beyond the participants implied meanings and thus go beneath the surface of what is said by the participants and thus “enters the laminal world of meaning”. (Charmaz 2009: 144). A major critique of co-construction is the possibility of having researcher bias and thus imposing the researcher own biases and preconceptions onto the research (Glaser 1998). This could lead to a lack of critical distance and inability to ‘hear’ other voices or the participants voices (Holloway & Galvin 2016). However, various steps and techniques were used in order minimise this which are highlighted in Sections 4.3.2, 4.5.2, 4.5.8, 4.6 and 7.3.3

The following sections provide a more detailed description of how constant comparison occurred during coding by means of memoing. In short, initial codes were compared with other codes, incidents were compared with other incidents, codes were compared with emerging categories (see Appendix 3 and 7), categories were compared with categories, and emerging theory with the literature (Holton 2007). In other words, the researcher compared the data and searched for similarities and differences, which directed the subsequent data collection (theoretical sampling) and co-construction of the emerging theory (Charmaz 2014). To initiate and facilitate initial coding, the basic grounded theory question – What’s happening here? (Glaser 1978) – was used. Furthermore, the researcher looked for social processes and actions of informal care rather than for themes and structure (Charmaz 2014) (see Appendices 3, 4, 5, 6, 7, and 19).

4.4.2 Coding

Different schools of thought about grounded theory have developed different labels and procedures for coding (Timonen et al. 2018). Glaser (1978) labelled data analysis as substantive coding (open coding and selective coding) and theoretical coding. Corbin and Strauss (2008) used the terminologies open coding, axial coding, selective coding, and theoretical coding. Charmaz (2014) uses initial coding, focused coding, and theoretical coding. Coding nomenclature differs among various schools of grounded theory because of the underpinning

philosophy that the researcher adopts for their research. Objectivist grounded theory researchers view data analysis as an objective process, see emergent categories as forming the analysis, see reflexivity as one possible data source, and prioritise the researcher's analytic categories and voice (Charmaz 2009, 2014). The constructivist grounded theory researcher acknowledges subjectivities throughout data analysis, recognises co-construction of data in reflexivity, and sees and (re) represents participants' views and voices (Charmaz 2009, 2014). Since this study adopted a constructivist approach to grounded theory, the researcher adopted Charmaz's coding process and nomenclature. Consequently, the coding process reflects the study's underpinning philosophy. The following sections discuss how the researcher used initial, focused, and theoretical coding.

4.4.2.1 Initial coding

Although, as explained above, different schools of grounded theory adopt different procedures for coding, all share a common aspect in the initial coding process. Initial coding involves opening up or segmenting the data as much as possible. However, Glaser (1992) cautioned against early cross-cutting of the data because it could force conceptual links between the data. In comparison, Charmaz (2014) emphasised looking for connections between data development even at the early initial stages of the coding. The researcher adopted Charmaz's (2014) analysis of data which involved initial coding as a process of defining, describing and extracting meaning from the participants' views and actions (Charmaz 2014). To open up data as much as possible, the initial coding was used to construct data segments with a short label that summarises and accounts for each piece of data (Charmaz 2014). Eventually, the coding process enabled raw interview data to be managed by systematically organising and condensing the data in code.

During initial coding, the researcher remained open (through reflexivity), stayed close to the data (by transcribing and reading the interviews for various times), kept codes precise and straightforward, constructed short codes, preserved the actions, compared data with data and moved quickly through the data analysis and coding (Charmaz 2014). This was done in an active attempt to avoid forcing the researcher's preconceived ideas and personal biases on the data. However, influence by the researcher was inevitable; Charmaz (2014) stressed the

principle of flexibility and insisted that the researcher must 'learn to tolerate ambiguity' and 'become receptive to crafting emergent categories and strategies (Charmaz 2008, p. 168). Charmaz's constructivist approach to grounded theory argues against a concrete, rule-bound, prescriptive approach to coding, stating that this stifles and suppresses the researcher's creativity (Charmaz 2008). As a researcher of this study, I constructed the codes trusting that they reflected what the participants meant, and described and defined the social process (Charmaz 2014). However, the codes are still my views about what I think is happening (Charmaz 2014). Moreover, I was already theoretically sensitive to some concepts related to the informal care by caregivers of patients with heart failure from preparing, reading literature, writing the PhD application and ethics application, and my past clinical and personal experiences. Therefore, I used memo-writing, prolonged engagement with the data, personal awareness and reflection throughout the interviews and data analysis to reflexively manage my own pre-existing views (see Appendix 4, 6, 7, 8, Memo number 26112016 in Section 4.2.1.2; and Memo number 10082016 in Section 4.3.2).

Line-by-line coding was used during the initial stages of this data analysis. At first, coding line by line seemed illogical as not every line contained a completed sentence and not every sentence seemed important. However, by adopting this type of coding, the researcher ensured that data was comprehensively analysed. This process helped him refocus at a later stage of data analysis and interviewing (Charmaz 2014). Moreover, this type of coding helped the researcher be more attentive to small nuances and fully engage with getting a sense of how the participants constructed the concept of informal care during admission and hospitalisation and the social processes that appeared to be influential and relevant. As recommended by Charmaz (2014) and Glaser (1978), an effort was made to use gerunds in the coding phase (e.g., fearing death, fearing of losing her/him, being let in, losing value of self). This was done to define implicit meaning and action, which gave the researcher direction to explore further data, which eventually helped him in making a comparison between data (codes vs codes and incidents vs incidents) and identifying the gaps and similarities in the data, as described in Appendix 3 (Charmaz 2014).

Focused coding involves using frequent code to shift through and analyse large amounts of data (Charmaz 2014). As data collection and analysis progressed,

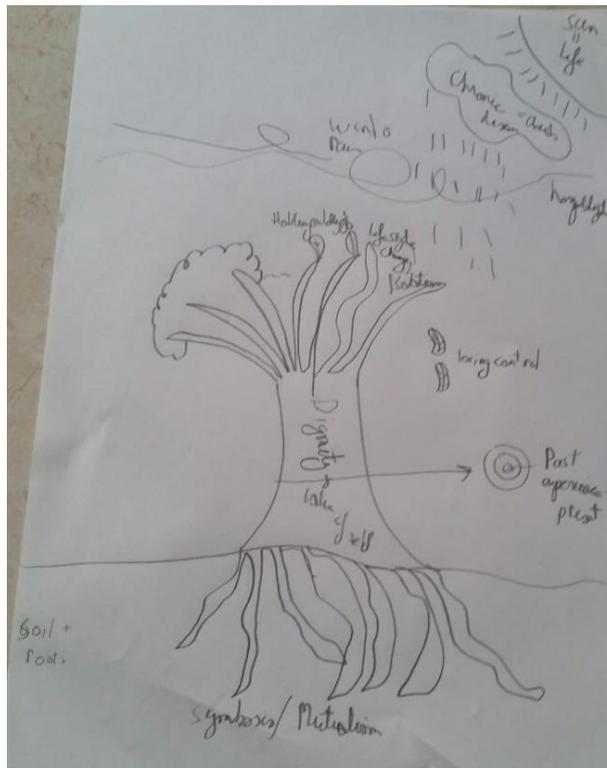
the researcher tried identifying recurrent codes or codes that seem particularly significant to the research area to refocus the initial codes (see Appendix 7 for an example). However, the researcher found it challenging to conceptualise the codes and elevate them to focused codes. But the initial coding stage resulted in a slow and tedious procedure. This may be because the researcher tried to code and open all the data rather than pragmatically breaking the data into codes that describe what was happening. The researcher focused all the data as fragments rather than what the participants said. To address the above, through discussion with the supervisors and consulting literature about grounded theory (Charmaz 2015, Buckley and Warning 2013, Glaser 1978, Birks and Mills 2015, Urquhart 2013), it was suggested the researcher adopt diagramming as a tool and strategy, which aided the analysis further.

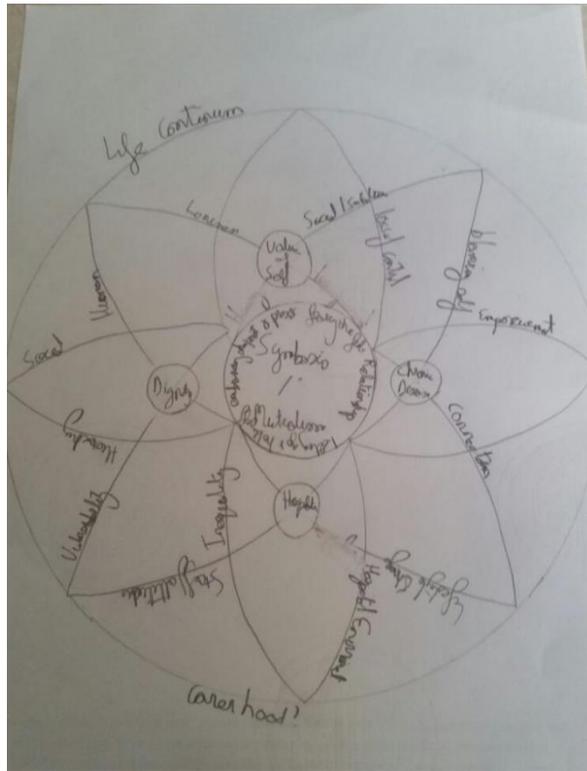
4.4.2.2 Using diagramming for focused coding

Focused coding should speed up the analytic work without discarding the detail in the initial codes (Charmaz 2014). It should be done relatively quickly and was described by Charmaz (2014) as a straightforward process. It involved coding the initial codes in a more focused and conceptual way (Charmaz 2014). However, this was not the case in the current research study. The researcher found it difficult to identify and select codes that represented most of the data collected. Diagrams, pictures, or images were used as alternative representations to gain insights into the setting and its participants and look for what the initial codes were revealing (Buckley and Warning 2013). Various grounded theory typologies use diagramming in various aspects of their analysis (Buckley and Warning 2013). Glaser (1978) suggested using diagrams to construct typologies during theoretical coding, whereas Strauss and Corbin (1990) support the practice of diagramming, together with writing memos, from the start of a study. By using diagrams and images in conjunction with writing memos, the researcher tried to investigate and reflect what the participants were trying to tell him by using the diagrams as a tool to generate, explore and record ideas (Buckley and Warning 2013). Diagramming is a creative tool, which the researcher used to operationalise, capture, and identify the properties and dimensions of the categories by using the logic of abduction (Birks and Mills 2015). Diagramming also helped the researcher organise, treat, and manage the initial codes that showed more theoretical reach, direction, and centrality (Charmaz 2014).

The following (Figures 1 and 2) is a brief example of how diagrams and memos helped the researcher in coding. Initial diagrams of all the codes resulted in a big chart and matrices, which were difficult for the researcher to interpret or conceptualise. Then the researcher started using diagrams and pictures rather than just words. The first diagrams were drawn up by going back to the data and using the initial codes as represented in the figures below:

Figure 1, Figure 2: Early diagramming involving initial codes and an attempt to identify the connection between codes (The corresponding memos of the figures can be found in Appendices 4 and 5)





The above figures were used to help the researcher analyse a large amount of data in a more focused way. However, Figures 1 and 2 did not explain a specific social process and were not adequately conceptual in nature. Furthermore, through reflexivity, feedback from the supervisors and memoing, the researcher acknowledged that these were not totally explained and/or did not reflect the data that the researcher had about the informal care of the informal carers during admission and hospitalisation. Therefore, the researcher used other forms of pictures to try to elevate the codes more conceptually:

Table 7: Memo No. 23092017

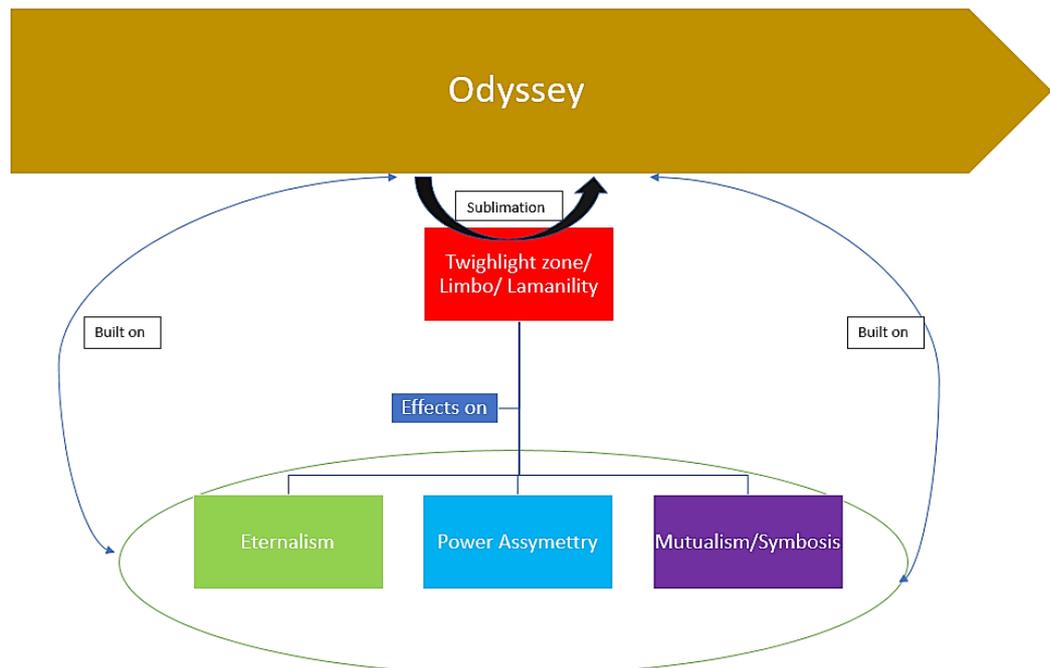
Memo	Codes
<p>When I saw these two pictures, they made me reflect. During their normal chronic lifestyle (odyssey), the carers had their puzzle complete (normal, adaptive chronic lifestyle). Whereas when the patient is admitted, the carer feels something is missing. Their level of guilt, fear, anxiety and vulnerability increases when their loved ones are admitted. This happens when the patient is admitted, and every time the carer leaves the patient 'alone' at the hospital. During the process of recurrent departing</p>	<p>Normal chronic lifestyle – odyssey</p> 

<p>(departuring), the carer is in a state of shock chaos and trying to understand why this happened and what will happen. This is based on the repressed fear of the death of their loved ones. During the stable phase (at home), carers have a sense of security and balance that everything is in place. However, when the acute phase kicks in and consequently admission, the carers are in a state of liminality (chaos, ambiguity, transition and disorientation). They do not precisely know what they expect: if their loved ones will die or come home. Due to the hospital's 'alien' environment, the acuteness of the illness, and recurrent departing (sublimation), their primary grief is somewhat confused. Most carers do not expect death and see no future without their loved ones living their present based on the past (eternalism). This fear of the unknown makes the carer react and behave to fill that void that a recurrent departure (departuring) brings. The carers respond and act to compensate for another stimulus or condition. This condition is fear of the death of their loved ones. The carers go out of their way to be near the patients for as much time as possible. Sometimes, carers even ignore their basic needs, 'ignore' other family members, sleep on uncomfortable armchairs, and change their lifestyle to be near their loved ones in the hospital. These reactions (motivating operations) are based on what they have learned during past experiences, their relationship (mutualisation), the support they receive during hospitalisation, and the phobia of death.</p> <p>What is really happening? Why is this worrying? What is the connection?</p>	<p>liminality, chaos, ambiguity transition disorientation sublimation eternalism mutualism</p> 
--	--

Consequently, more memos and diagrams were devised on coding the above memo (in **bold**). The following diagram (Figure 3) was eventually developed to summarise what, until that moment, the researcher saw from the data through

the process of initial coding, diagramming, coding the memos, and re-naming and focusing the initial coding.

Figure 3: Early diagramming of the emerging concepts



However, Figure 3 did not reflect the actual process of informal caring during hospitalisation, and therefore did not fit with the data. Being reflexive and going back to the data did not explain what the participants discussed in the interviews. However, through memoing, sorting of memos, sorting of diagrams and pictures, and again going back to the data, participants appeared to be in a state of liminality – the act of being in a transition/lost/uncertain (anger, suppressed fear, guilt, anxiety, vulnerability, shock, loneliness, ambiguity, confusion) (see Appendix 6). However, liminality did not seem the correct word to describe the social process involved. Therefore, when reading about liminality, the researcher encountered the word ‘vigilance’. A short and quick memo about vigilance showed that vigilance could explain what was happening:

Vigilance is the action or state of keeping careful watch for possible danger or difficulties. Thinking of the above meaning, I can see vigilance in the collected data. Informal carers during admission and hospitalisation are always present in one way or another to carefully watch their relatives. Like a vigilante, the informal carers during admission and hospitalisation conduct a double life (duality), struggle to catch up to be near the patients (being let in), and are always in an anxious state, waiting and

worrying (*vigil by the bedside*). Therefore, vigilance is starting to feel like the central organising category.

(Memo Number 10102017)

Therefore, as a researcher I had go back to the data and review and re-code various quotes which were initially coded which could be attributed to a main category of vigilance, as seen in the appendix 24. The researcher refocused other initial codes in three main categories: 'being let in near the patient', 'duality' and 'vigil [by the bedside]' with the overarching category being vigilance, and a new diagram was devised, as can be seen in Figure 4.

Figure 4: Early auditioning of vigilance as the core category



4.4.2.3 Theoretical coding

Theoretical coding means the usage of codes from prior theories and literature to integrate abstract and conceptual categories in the analyses (Charmaz 2014). From the data, the focused coding merged into theoretical coding. The core category of vigilance with the major subcategories of duality, being let in, and vigil by the bedside continued to resonate compared to data from the first interviews. The early and rough diagrams in the above sections eventually became Figure 5, an early model of the proposed substantive theory. The model was presented to the participants through theoretical sampling and further interviews. By coding, re-coding, regular discussions with my supervisors and memoing, advanced data analysis continued by theoretically sampling the participants and sampling the literature. Appendix 20 shows how a memo after a supervision meeting was used to theoretically code and recode the categories by sampling the literature

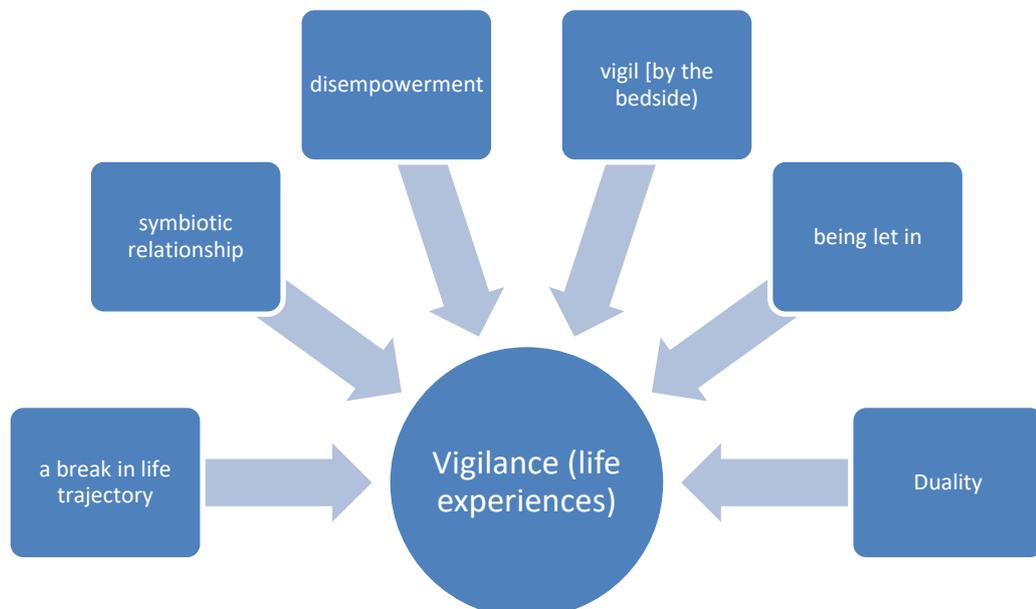
according to the emerging theory and data and using diagramming to aid me as a researcher in reorganising the emerging theory. Borrowing language from extant theories²³ helped me explain this significant social process in theory. The following memo gives an example of how borrowing terms from the status quo bias theory helped explain the emergent theory:

During a sudden onset of chronic illness (a break-in-life trajectory), participants experience a status bias. This is an emotional bias in which the participants prefer the current state of affairs that is stable at home. The current baseline (status quo) of being at home is seen and taken as a reference point by the patient, and informal carer, and any change (admission) from that baseline (home) is perceived as loss (see data in interviews 1, 2, 3, 4, 5, 10, 12, 13, 14, and 15). The status quo of preferring to stay at home could be defined as the status quo ante. That is when the current state of affairs is objectively superior to the available alternatives (admission and hospitalisation). This status quo bias affected the participants' decision-making by informal carers delaying their choice of going to the hospital.

(Memo Number 22112019)

Further elaboration of this diagram ultimately resulted in the substantive theory summary presented in the findings chapter.

Figure 5: Early auditioning of the proposed substantive theory



²³Such as Schlossberg's transition theory (1981, 2011), status quo bias theory, and others.

4.4.3 Memo-writing

Memo-writing is the cornerstone of quality, which captured the researcher thoughts, feelings, insights and ideas about this research project and was used throughout the research process (Birks and Mills 2015). Memo-writing is a pivotal tool to constructing a theory, especially in constructivist grounded theory (Charmaz 2014, Kenny and Fourie 2015). Writing the memos helped the researcher 'to stop and analyse my ideas about the code in any – and every – way that occurs to you during the moment'. (Charmaz 2014, p.a 162). Being a novice in memo-writing for a grounded theory study, the researcher adopted some writers' strategies as a prewriting exercise (Charmaz 2014). Clustering and freewriting were the two strategies adopted, and both helped the researcher write in a non-linear way and thus liberate his thoughts from linear logic (Charmaz 2014). Clustering involved prewriting shorthand using non-linear, visual and flexible techniques to understand and organise the research material (Charmaz 2014). At the same time, freewriting means putting pen to paper and starting to write freely, quickly and comprehensively without taking into account grammar errors, logic or audience (Charmaz 2014). These exercises helped the researcher liberate his creativity and flexibility, which ultimately helped him be more interpretive, intuitive, and impressionistic during the coding procedure (Charmaz 2014, Kenny and Fourie 2015). Furthermore, these two techniques helped the researcher's memo-writing become spontaneous rather than forced or mechanical. Examples of clustering and focused free-writing methods using diagrams and memos used in the study are represented in Figures 1, 2 and 3 and Appendix 3, 4, 5, 6, 7.

Birks, Chapman and Francis's (2008) mnemonic of MEMO (mapping research activity, extracting meaning from data, maintaining momentum and opening communication) will now be used to explain further how memo-writing was used for this grounded theory research.

- **Mapping research activity:** For the audit trail, a methodological diary or journal was adopted in which the researcher jotted down methodological dilemmas, directions and decisions (operational memos) (Charmaz 2015). An example of an operational memo can be seen in Section 4.3.2. A brief audit trail built on the operational memos and on how and why the researcher has used diagramming in the data collection and analysis

phase can be seen in Section 4.4.2.2. However, the researcher devised a table that included every step and activity in order to understand the research procedures better. This memoing was found very straightforward and provided the novice researcher with an opportunity to acquire further skills and confidence in memo-writing (Birks, Chapman and Francis 2008).

- **Extracting meaning from data:** Memos were used during the whole data collection and analysis process to extract 'what is actually happening in the data' (Glaser 1978, p. 57). Various strategies gave the researcher conceptual leverage from the data collection and analysis. Various examples of these memos are present throughout this chapter and Appendices 3, 4, 5, 6, and 7.
- **Maintaining momentum:** Memos were written frequently by allocating protected time and space for memo-writing. However, ideas and thoughts were written as soon as they surfaced, without any restrictions.
- **Opening communication:** As Clarke (2005) suggested, a memo data bank was kept and continuously updated, including original memos, unedited free writing (both computerised and handwritten), images, diagrams, and other text writing. Diagramming with extended memos took place during the initial, focused and theoretical data analysis stage, and enabled communication with the supervisors about the main codes, major categories, concepts, and central organising phenomenon.

4.5 Ethical considerations

One of the major criticisms of the grounded theory approach in the early days was the failure to address the ethical issues (Olesen 2007). This could be because the grounded theory was devised as a set of approaches to data analysis. Considering ethical issues during a study is important to obtain ethical clearance from the research ethics board (Birks and Mills 2015). One must keep in mind that ethical issues will affect the analytic process of a grounded theory study mainly during coding, theoretical sampling, and writing the account (Olesen 2007). Moreover, grounded theory research is flexible, and the data collection and analysis could change as the theory from the co-construction of data is collected and analysed (Birks and Mills 2015). This could be problematic in view of ethical issues during submission to ethical boards because the researcher can never predict what will happen at the beginning of the study. However, the

following is a thick account of how ethical issues were addressed and how this affected the researcher during data collecting, analysing and writing the study.

4.5.1 Permissions and gatekeepers

Data collection did not start before receiving full ethical approval and institutional permissions from the above entities. After the ethical approval from the University of Brighton was obtained, ethical approval was sought from the University of Malta Research Ethics Committee since the actual research project was to be carried out in Malta. Furthermore, authorisation to conduct this research study was sought from the General Hospital's management and respective consultants. This approval emphasised that the interview schedule and/or the participants could change due to the nature of the data collected and theoretical sampling. As pointed out in Section 3.3.3, the interview schedule changed from addressing burdening, role change, participation and decision-making to addressing vigilance, the dual role, vigil by the bedside and being let in. On the other hand, on submission of the ethical proposals, it was pointed out that the study population, besides informal carers and patients, might contain healthcare professionals at a later stage. This didn't happen as the data did not indicate the need to recruit healthcare professionals.

This stage of submissions and authorisations from all the boards and gatekeepers concerned was time-consuming (from February 2015 to May 2016), and no data was collected. However, during this time period, the researcher learned not only about the ethical issues, but how to prepare for the study by devising the interview guide, preparing the resources, reflecting on how to recruit and identify 'excellent' participants, planning for the data collection and analysis, and much more. As Charmaz (2015) stated, preparing for a grounded theory study can be stressful but is crucial for a successful study, especially for a novice researcher. Therefore, by devising the ethical forms and proposal, the researcher learned how to conduct a grounded theory study that is congruent ethically and even ontologically and epistemologically (as explained in the above sections).

4.5.2 Power relationships

Unequal power relations are inherent in patient–health professional interactions, and therefore a need was felt to attempt to minimise the effects this may have had on the recruitment process (Birks and Mills 2015). While it might not be

possible to totally eliminate the perception of power imbalances, a set of strategies to curtail it to a minimum were used; these were explained to the participants before opting in and during the whole duration of the data collection process in order to try and minimise the power imbalances. This was to ensure that patients' and informal carers' agreement to participate in the study was given voluntarily and without coercion. Furthermore, all the following information was given to the participants beforehand in the information sheet (see Appendices 8, 9, 10, and 11):

- 1) The interviews were conducted in a setting and on a date/time that the participant chose. Participants had a choice between their home or hospital or University premises. Twenty participants chose their own homes for the interviews, while one chose hospital premises.
- 2) Assurance was given to the participants that the interviews were not 'tests', and that there were no right or wrong answers, and that the researcher was seeking to understand their experience, of which they were the expert.
- 3) The participants were reminded before starting the interview that the researcher's role in the interview was that of a researcher and not of a practitioner.
- 4) Information regarding the approximate length of the interview and a follow-up interview/theory verification was given beforehand to the participants to avoid exploiting the researcher-partnership relationship.
- 5) Patients' and carers' willingness to participate was checked throughout their involvement in the study (including being aware of non-verbal cues such as their body language).
- 6) It was restated that the participants can opt out of the study at any time without giving a reason and without penalty. Additionally, if participants did not want to answer a question, they did not have to. It was explained to the participants that, due to the nature of the study (i.e., co-construction of the meaning of the data between the researcher and participant and the concurrent data collection and analysis [Charmaz 2014]), if a participant withdrew after an interview had been conducted and analysed, it might not be possible for the data to be disaggregated from the analysis. None of the participants interviewed for the study has withdrawn.

The above procedures ensured that the participants' exploitation was maintained to the minimum, counteracting the imbalance of power and establishing reciprocity between the researcher and the participants. When the researcher was devising and reflecting on the above strategies, one of the main issues that arose was to adopt a non-judgemental stance towards the participants and eventually during the data collection and analysis. In fact, before commencing this study, the researcher had the impression that informal care was a burden, especially during hospitalisation. This was evident in the first non-committal literature review presented in the research proposal, where one of the main themes was burdening. However, during the first interviews, the researcher recognised that the participants never described their informal care as burdening but as their duty. Furthermore, the researcher adopted ice-breaking strategies to build rapport and minimise the power relationship between the researcher and the participants (see Section 4.3.2, Memo Number 10082016). Oakley (1981) used a famous and important notion of 'no intimacy without reciprocity', which involves the researcher investing time by answering questions from the participants and sharing personal ideas and details about the subject. Furthermore, this ensured that the researcher put his personality in the research process to establish a less hierarchical relationship (Birks and Mills 2015, Charmaz 2015). Eventually, this rapport-building by counteracting imbalances of power led to a sense of protection and safety for the participants, which enhanced the researcher and the participants' rapport, which eventually resulted in co-construction of data.

4.5.3 Potential benefits

The information and data collected were used in building a theory that could improve subsequent patient and informal carer experiences during admission and hospitalisation. There were minimal direct benefits for the participants in contributing to the study. This was fully explained to the participant in the information sheets and before the commencement of the interviews (see Appendices 8, 9, 10 and 11).

The direct benefit observed for the participants of this study was the opportunity to discuss their experiences. Four participants (Daphne, Dominique, Danielle and Daryl) expressed their feeling of liberation by talking about their experiences during the interviews. They stated that they had no time to speak with anyone

else about the experience of admission and hospitalisation of their relatives with CHF. The interviews made them feel listened to, when they were usually unwilling to talk with someone else. The participants expressed the sensation that their life is always on the go and full of events (because of recurrent admissions and hospitalisation of their relatives with CHF and their personal life), and that they never stopped and thought about it. Consequently, these interviews made them express their concerns and reflect on their experiences, feelings, and current situation. Although this could not be considered a direct benefit, it made the participants feel better.

4.5.4 Participant information and consent

To adhere to the ethical principle of respect for human dignity, autonomy and the right to full disclosure, the participants were presented with an information sheet and a consent form. Once the participants contacted the researcher to express their interest in participating and met the inclusion and exclusion criteria, the participant information sheet and a consent form (see Appendices 12, 13, 14 and 15) were sent. The information sheet and the informed consent form were designed in collaboration with the patients with CHF and their carer representatives (who were not included in this study) to ensure that it was understandable, and both were made available in Maltese and English. This again enhanced the co-construction of data between the researcher and the participants. Both patients and informal carers were invited to sign an informed consent form. Potential participants were given no less than 24 hours to consider participation.

Time was given to the participants to ask questions and clarify any issues about participation in this research. Moreover, just before the interview, the same information was repeated verbally to ensure ongoing consent was achieved. Furthermore, the researcher gauged the capacity to consent by asking the participants what they understood about this study, what this research involves, and the main risks and benefits (Tremblay et al. 2007, General Medical Council 2008). If the researcher had any doubt about their capacity to decide or give their consent, the participants would have been excluded from the study. However, with the help of the gatekeepers and the recruitment strategy using the inclusion and exclusion criteria, 'excellent' participants were identified, contributing to the study by giving 'excellent' data (Morse 2007).

As explained in Section 4.2.1.3, some participants refused to sign the informed consent when they were given the form just before the commencement of the interview. These participants were excluded from the study. Furthermore, reflecting on the above procedures by providing the information and informed consent, the participants felt safer and thus eventually opened up more, which enhanced rapport-building and co-construction of data.

4.5.5 Confidentiality

Pseudonyms were given to the participants. These were used during transcription of the recorded interviews and writing-up/publication of findings to protect their identities and ensure that data cannot be linked to the individual participant who supplied it. The researcher transcribed interviews. Access to the interview transcripts was restricted to the researcher. Identities of all the participants were not and will not be disclosed in any reports/publication/conference presentations of findings. Specific information about the locality of the study will not be given. This was made known to the participants in the participant information leaflets. Since this study was primarily composed of face-to-face interviews, confidentiality was a challenge since the participants (informal carer, patient, and researcher) disclosed information. However, as noted in Section 4.3.4, from the researcher's experience, informal carers and patients complement each other, hence, for practical and safety reasons (for the participants and researcher), it made more sense to interview both together rather than individually. However, the participants could be interviewed alone or together (patient and informal carer). All the participants chose to be interviewed together.

4.5.6 Disclosure of confidential information beyond the initial consent given

Furthermore, to further safeguard the confidentiality of the participants, it was explained that only conditional confidentiality was possible. Therefore, the limits to confidentiality and information on how any disclosures will be managed were explained to potential participants through written and verbal information about the research, and reinforced during the consent process. The participants were informed that the interview content was private unless they disclosed that they or someone else was at risk of harm. If such a disclosure was made, they would have been told that the researcher may need to talk to someone else (e.g., a clinician) and that this would be agreed with them. In view of this, a distress protocol was devised (see Appendix 2) to help the researcher deal with such

situations. Based on previous clinical experience, the researcher was aware of the escalation of policies according to the clinical governance procedures. If an issue arose, this process would have been followed (University of Brighton 2015).

4.5.7 Data storage

The study complied with the principles set out in Malta Data Protection Acts (2018). It conforms to the policies of the host hospital concerning appropriate storage, restricted access and disposal arrangements for personal and research data. As such, digital audio files and transcripts from the interviews were stored separately and securely from a site file containing any written identifiable information (including a participant identification list) related to the study, in locked filing cabinets in the researcher's office within the University of Malta. All electronic data were stored on a password-protected computer and password-protected USB stick. Immediately after each interview, the audio data was transferred to the password-protected computer and erased from the audio digital voice recorder. After completing the study, tapes will be erased and personal data shredded. All other documentation will be archived for ten years (University of Brighton 2015).

4.5.8 Researcher safety and role conflict

During the interviews, some participants asked for advice about aspects of their treatment, or they became distressed or upset. Due to the nature of the subject under examination (acuteness during admission and hospitalisation), sensitive issues that would cause distress to some participants could have arisen. A distress protocol was devised for this study, and if activated (see Appendix 2), the interview would have been stopped immediately, and the participants would have been given a choice to have counselling with an appropriate support service, if needed. Five interviews were stopped for a few minutes during the data collection because participants felt distressed, especially when asked about their future. The distress protocol was evoked, and the participants were given a choice to stop the interview. However, all the participants chose to continue with the interview.

When participants asked advice about certain aspects of their treatment, this could have resulted in role conflict, whereby it may become difficult to distinguish between research and therapeutic roles. Therefore, during the interviews, the

researcher reminded the participant that his role was that of an investigator and any advice sought about aspects of treatment would be directed to the appropriate person (their GP or HF clinic). Since most of the interviews were conducted in the participants' home setting and some of them took place outside of regular working hours, lone-worker policies were followed, which included informing colleagues and supervisors of the timing and location of interviews and ensuring that a mobile phone was carried at all times (University of Brighton, 2007).

The above strategies ensure that the researcher is part of the study by being a researcher rather than a practitioner. However, the researcher did hold back from occasionally expressing his experiences²⁴ and views on the subject with the participants, which conforms to the constructivist nature of the study. This may have led to a difficult or awkward position where there is a fine line between being a researcher and being a practitioner. To avoid pitfalls or over-influencing the participants, reflexivity using memoing was engaged throughout the process, as explained in the next section.

4.6 Methodological rigour

Methodological rigour was enhanced by adopting the strategies proposed by Birks and Mills (2015) of influential factors for quality in grounded theory: research expertise, methodological congruence, and procedural precision, all outlined below. Additionally, Lincoln and Guba (1985) suggest that methodological rigour in a qualitative study comes from establishing trustworthiness by considering the following elements: credibility, dependability, confirmability, and transferability.

4.6.1 Researcher expertise

For a research project to be successful, there is no need to be an expert or an experienced researcher (Birks and Mills 2015). However, a process should be initiated from the beginning of the project to increase the knowledge, skill, and professional attributes in order to have a successful research project (Birks and Mills 2015). The researcher started his journey with a pre-existing set of skills and knowledge (as described in Chapter 1), which were enhanced through learning activities to develop competence and confidence with the various stages and

²⁴Such as when the participants were asking about their treatment or about a procedure that they had done in the past.

steps of the research project. As a doctoral student, the researcher had to identify what to research, prepare for multiple documents such as the research plan proposal, interview schedule and the interviews per se, prepare for the annual doctoral conference presentation and the annual progression report, evaluate throughout, and disseminate the research output. This helped the researcher increase his knowledge about the subject and his skills as a researcher. In addition, the researcher was continually reading and accessing online resources not only on constructivist grounded theory but also on other schools of grounded theory. Participating in a grounded theory special interest group and online research communities helped the researcher enhance his skills.

Furthermore, self-awareness, clarity of purpose, commitment to hard work, and internal motivation to do research are additionally described by Corbin and Strauss (2008) as the personal and professional researcher characteristics to enhance the quality of a study. Commitment to hard work and internal motivation for this research arose from the personal and professional background (see Chapter 1), but being a self-paying student made the researcher more aware and committed to this study. Self-awareness and clarity of purpose were maintained through memoing, peer debriefing, member checking, participants' involvement and reflexivity (see Sections 4.6.2.1, 4.6.2.2, 4.6.2.3, and 4.6.2.4). However, one must point out that the researcher felt overwhelmed by the various grounded theory terms and complexities at the start of the project. Stern (2007) and Birks and Mills (2015) recognise this uncertainty and emphasise that for a researcher to truly understand the grounded theory, they must pass through producing one themselves. The researcher is not claiming that now he is an expert in the grounded theory process, but he has a clearer understanding of what a grounded theory entails. He acknowledges it will always be a work in progress.

4.6.2 Methodological congruence

Birks and Mills (2015, p. 63) state that methodological congruence 'occurs when there is accordance between your personal philosophical position, stated aims of your research, and the methodological approach you employ to achieve these aims'. As discussed in the previous chapter, a relativist ontology and constructivist epistemology were adopted for this research. Consequently, this led to choosing a constructivist grounded theory as a research methodology underpinning the research's theoretical framework. The above sections explained

and explored the specific methods used for collecting and analysing data, showing methodological congruence during the operationalisation of the study with strategies and tools consistent with a constructivist grounded theory approach. In view of this, the credibility of this study in being authentic to constructivist grounded theory was enhanced by using reflexivity, member checking, participant involvement and peer review, which will be expanded in the below sections. Additionally, transferability was made possible by providing extensive background and context to the study in the first chapter and by using thick descriptions in presenting the findings in the next chapter. Therefore, credibility and transferability will be explained in more detail in relation to the above components in the following sections through reflexivity, participants involvement and peer review.

4.6.2.1 Reflexivity

As discussed in Section 3.3.3, together with literature review and theoretical sensitivity, reflexivity is one of the highly debatable topics in grounded theory literature. As pointed out in the previous chapters, reflexivity was used as a teaching moment for the researcher during the whole research process. Reflexivity depends on the study's underpinning philosophical stance, and therefore, Charmaz (2014) stresses the importance of engaging in reflexivity as an integral part of a constructivist grounded theory research study. Since this study was based on a constructivist approach, to enhance the credibility of this study, the researcher needed to articulate his personal views and insights regarding the phenomenon explored (Chiovitti and Piran 2003) and therefore engage in reflexivity. Reflexivity includes examining the researcher's interests, positions and assumptions and how this influences the research study (Charmaz 2014).

Reflection was done mainly by post-interview reflective accounts, field notes during the interviews, extensive reflective memo-writing, writing various reports, discussions with supervisors and peers, presenting papers during various conferences, and a research diary that was kept to capture the social process of the research study. To achieve this, various strategies highlighted above were used in the different phases of the research process:

- In the initial stage of posing a research question and deciding on the study's design: As highlighted in Chapter 1, the topic evolved from my

personal and professional interest in learning something new about informal care and developing a theory about informal care in admission and hospitalisation. These personal and professional experiences about the topic of informal carers led to precious insights and perspectives that could hardly be accessible to a researcher unfamiliar with the subject of informal care (Mruck and Mey 2007). Reflection at this stage involved various regular meetings/discussions with my supervisors regarding the topic, discussion with my colleagues, friends, and students, participating in the annual doctoral college conference, presenting in various local conferences about the subject, and writing and submitting the ethical approval forms and research plan approval. This was done to answer questions such as:

- What understanding am I aiming for?
- What kind of knowledge can I possibly gain?
- How do I understand the role of the researcher?
- Why this research?
- Why is this my passion?

(Finlay and Gough 2003)

- During sampling and data collection: The importance of theoretical sampling in grounded theory research is well documented in the literature and discussed in the previous sections of this chapter. Reflexivity should be used as a strategy to show how theoretical sampling was operationalised and should also be used to prepare for data collection and during the data collection. Memo Number 26112016 (Section 4.2.1.2) shows how reflexivity based on the data and previous interviews helped me in theoretical sampling. Furthermore, Memo Number 10082016 (Section 4.3.2) shows how reflection after conducting an interview helped improve my interview skills. This post-interview reflection was used as a self-monitoring tool to limit the influence of the researcher and highlight the pre-existing constructs during data collection (Chiovitti and Piran 2003). Additionally, adopting the strategies highlighted in Section 4.5.2 ensured that the power imbalance between participants and researcher was minimized, and thus lessened the researcher's influence on the data collection (Mills et al. 2006). Besides the reflective diaries and checklists,

Section 4.3.2 showed how support from colleagues, friends, role play, discussions with PhD supervisors, reflexivity, and literature helped me prepare for the interviews by devising an interview checklist and an interview process (Mruck and Mey 2007).

- During data analysis: during the concurrent data collection and data analysis, the help of 'outsiders' via regular discussions with the supervisor and peers helped me be reflective during data analysis (Chiovitti and Piran 2003). Furthermore, submitting my transfer document and presenting it at the annual doctoral college conference helped me reflexively. Adequate timing between a set of interviews (Table 4 in Section 4.2.1.3) gave me time and breathing space to code, recode, reflect, and interact with the data. At the same time, Table 7 (Section 4.4.4) shows how reflection on diagrams was used to analyse the data. The memo in Appendix 4 shows how the researcher's past experiences and perceptions were identified, reflected, and brought into the data analysis.

4.6.2.2 Member checking

The next step identified by Chiovitti and Piran (2003) is to check the generated theoretical construction against the participants' meaning of the phenomenon (member checking). A debate arises about the value of this type of verification in grounded theory research. Glaser and Strauss (1967) argue that the researcher should focus on generating theory rather than verifying it. Elliot and Lazebatt (2005) argue that checking the emerging theory is an integral part of the constant comparative method of grounded theory, whereas Charmaz (2014) argues that the researcher needs to co-construct the theory with the participants rather than verify it. However, the constructivist approach to the grounded theory implies that checking and co-constructing the emerging theory with the participants themselves is essential (Mills et al. 2006). This is considered an important strategy to promote participants' involvement in the research process and to be congruent with the philosophical stance of this study (Mills et al. 2006). The main strategy for member checking adopted in this study was during the interviews, in which the researcher needed to be 'attuned to what each participant is saying, be theoretically sensitive to what this means for the developing theory and directing or following the interview accordingly' (Birks and Mills 2015, p. 73). Therefore, during the interviews, the researcher used restating, summarising, and paraphrasing to enhance member checking.

Furthermore, by adopting interviews with the informal carers and patients with CHF together improved the notion of member checking by having the participants supplement each other, ask questions to make the point clear, and help each other express incomplete thoughts (Morgan et al. 2013, Morgan 2016). These strategies were another way of co-constructing meaning between the researcher and the participants, which is part of the constructivist approach taken for this research study. Furthermore, re-interviewing the previous participants and recruiting new participants for theoretical sampling was not used to validate the theory but to facilitate the ongoing analysis by adding information in areas that were not yet fully explained (thus enhancing theoretical sufficiency), and to generate a theory.

4.6.2.3 Participants' involvement

During the research study proposal planning, participant involvement included showing and receiving feedback on the planned interview agenda and participant information sheet from healthcare professionals, patients with CHF, and informal carers. In the proposal phase, it was unknown whether interviewing healthcare professionals would be required for the study because the research objectives focused on informal care by caregivers of patients with CHF. It was anticipated that the nature of grounded theory data analysis could lead to theoretically sampling healthcare professionals. Consecutive data analysis indicated that healthcare professionals were not needed for the study, but the researcher remained open to the possibility in case theoretical sampling led to that direction. Furthermore, the inclusion and exclusion criteria were deliberately left broad (with no limitation on the physical condition of the patient or informal carer, what type of relationship there is between the informal carer and the patient, or the number of admissions) to allow flexibility for different types of informal carers and patients with CHF to participate. This allowed, as the study progressed, for the use of use theoretical sensitivity to guide the sampling process.

Moreover, the topic guides were used to structure and facilitate the conversation. The areas for discussion were an outline, and interviewees were encouraged to identify their concerns. As interviews and analysis progressed, the topic guide was altered to include emerging themes and issues.

4.6.2.4 Peer debriefing

Peer debriefing or review involved sessions or meetings held with objective peers (research supervisors), who are experienced in methods of qualitative research or the phenomenon being studied or both. The purpose of the meetings was to review the researcher's progress in data collection and analysis (Polit et al. 2001). These peer review sessions enhanced concept clarity (Chiovitti and Piran 2003). In the present research study, such peer debriefing occurred during supervisory meetings with the academic supervisors throughout the research process. Furthermore, another form of peer debriefing was done in presentation meetings in the annual progression reviews and the annual doctoral college conference. Further peer review was done while discussing the research study at the university grounded theory special interest group and other research students. In these conferences, discussions and meetings, the researcher was open to the audience's and the supervisors' feedback and criticism to refine or build on the emerging theory or improve his researcher skills.

4.6.2.5 Transferability

Transferability is the extent to which the findings may have applications in similar situations or populations elsewhere (Savin-Baden and Major 2013). This was addressed by providing a detailed and thorough description of the research context (Polit et al. 2001). This was represented in Chapter 1 through an introduction to the subject, local context, and my past experiences. Chapters 2 and 3 described and discussed the philosophy underpinning this study and how this affected the methods for data collection. Furthermore, during the interviews, one of the researcher's objectives was to obtain thick and detailed data descriptions (Denzin and Lincoln 2008, 2011). The findings chapter has rich detail and contextualised accounts of the participants' views and experiences. This was done by using the participants' own words and language to build up the grounded theory construction, and memoing from the researcher in the final report, which contributed to the credibility of the findings (Chiovitti and Piran 2003). These strategies should allow the reader of this research to judge whether the theoretical concepts of the research findings could be transferable to other settings while also evaluating the quality of the study (Chiovitti and Piran 2003).

4.6.3 Procedural precision

A final and crucial step in producing a quality product, as discussed by Birks and Mills (2015 p.), is to pay 'careful attention to the rigorous application of grounded

theory methods'. Throughout this chapter, the researcher explained how core aspects of grounded theory research were carried out for this study, which included: delaying a comprehensive literature review until the later stages of the research, theoretical sampling, theoretical sensitivity, concurrent data collection and analysing, coding, reflexivity and memoing. Birks and Mills (2015) suggest that to ensure procedural precision, one must pay attention to maintaining an audit trail, managing data resources and demonstrating procedural logic, which will contribute to the dependability of this study. For this study, the advanced options within Microsoft Word and the Windows operating system helped the researcher organise, store, and search data for data collection and analysis purposes. However, without minimising the importance of audit trail (data collection and analysis), the outcome of a second researcher's experience with the data is unlikely to mirror the outcome of the original research (Birks and Mills 2015). Additionally, memoing was described as the cornerstone of quality by Birks and Mills (2015), which was maintained during all the phases of this research process.

Finally, the dependability of this research also came from reporting the entire research process and ensuring the ethics and governance requirements were followed correctly. Confirmability was further achieved by keeping a detailed audit trail of all the research activities, maintaining a reflective research journal, securing all the data, and being transparent about all aspects of the research design.

4.7 Summary

This chapter discussed and explained the research design and methods used while collecting, generating, and analysing data congruent with this study's philosophical underpinning. Semi-structured in-depth interviews using dyadic interviewing were the tool through which data was obtained for the study. The analysis process included the specific coding techniques of the initial line-by-line coding, as well as focused coding (using mainly diagramming and constant comparison), theoretical sampling and theoretical coding. The study's methodological rigour was also evaluated to demonstrate that the theory generated is credible and stems from high-quality research. Ethical considerations and implications for methodological rigour concluded this chapter, with the findings from the study following in the upcoming chapter.

Chapter 5: Findings

5.1 Introduction

This chapter will present the findings generated from the analysis of the 15 interviews conducted with 21 participants about the meaning of informal care of patients with CHF during admission and hospitalisation, and the influencing social process. A representation of the verbatim quotations of the participants in the sections below will be used to illustrate and ground the substantive explanatory theory which emerged from the findings. As far as possible, the researcher has endeavoured to ensure that the participants' perspectives were privileged throughout. Still, a combined voice will be presented to enhance the development of the theory.

This research study aimed to develop a theory that explains the social process involved in the informal care of a patient with CHF during admission and hospitalisation. This was done by abiding by the methods discussed in Chapter 4, keeping in mind the philosophical assumptions underpinning this study (see Chapter 3) derived from the research questions and aim. However, the researcher recognised that the account of the participants was multi-layered, intertwined and sometimes contradictory because each person had their own experience. Consequently, the theory was represented as a process with categories and codes within them, and although differentiated, they were not separated. Each was interlinked and encapsulated the essence of the social process described and discussed by the participants.

Pseudonyms were used to maintain the participants' anonymity in accordance with data protection guidelines (Data Protection Act Malta 2018). The quotations were represented in an English-translated version of the Maltese language; a more detailed description of the complex nature of translation and the inherent problems encountered were presented in Section 4.3.5. When possible, the Maltese language was translated to English, showing the original meaning and the participants' expressions. However, some idioms specific to the Maltese culture were difficult to translate into English; in such cases, an explanation of those phrases and colloquialisms has been presented to accompany the narrative and bring meaning to those idioms which cannot be translated. Nevertheless, to maintain the integrity of the data, the quotations were translated with the help of the local supervisor (see Section 4.3.5).

This chapter begins by introducing the study participants in order to provide context to the findings of this research. The theory of informal carers' vigilance during admission and hospitalisation will be presented in the following way: the social process of informal care during admission, the importance and the social process of informal care for patients with CHF and the social process of informal care during hospitalisation. The chapter will go on to present the core category of participants, followed by the influencing factors and effects.

5.2 Participants' background

The following is a brief background of the participants in this study. The background of the participants was presented to give the reader a deeper understanding of the context of this research study. The background information on the subject, the local Maltese context, the researcher's professional and personal background (presented in Chapter 1), and the initial literature search (presented in Chapter 2) will all enhance this study's methodological rigour and trustworthiness. This is important because this study aims to interpret the social process involved by situating the participants and data in their historical context, time, space, and position (Charmaz 2009).

Each pseudonym sheds some light on the corresponding participant's gender and whether they are patients or informal carers. Thus, pseudonyms starting with the letter P are used for participants who are patients with CHF, D for participants who are the daughters of patients with CHF, W for participants who are the wives of patients with CHF, and H for participants who are husbands of patients with CHF. For example, Pamela is a 60-year-old patient and Harry, her husband, is her informal carer, whereas Patrick is a patient and Wendy is his wife and informal carer. Furthermore, the participants' status will be represented in brackets after the pseudonyms. An overview of the characteristics of the 21 participants (13 informal carers and 8 patients) in this study is presented in Table 8.

Table 8: Participants' demographics and characteristics

Interview	Participants' Pseudonyms	Age	Living status	Admissions 6 months prior to interviews	Support to informal carers (IC) ²⁵	Hours of contact between IC and patient while at home ²⁶	Hours of contact between IC and patient while hospitalised ²⁷	1 st set of interview data (purposive sample)	2 nd set of interview data (theoretically sampled) ²⁸	3 rd set of interview data (theoretically sampled) ²⁹
1 st	Pamela Lee (Patient)	61 years	Same home	10 times	Minimal ³⁰	24 hours	8 to 12 hours	15 th July 2016		
	Harry Lee (Husband)	65 years								
2 nd 6 th	Patricia Bailey (Patient)	84 years	Not the	2 times	Yes	8 to 12 hours	4 to 6 hours	2 nd August 2016	20 th March 2017	

²⁵ Support refers any type of help and support that the informal carers received from siblings, friends and others during the one year prior the interview.

²⁶ Average hours of contact prior the interview (six months) between the informal carers and the patients while they were at home as stated by the participants themselves.

²⁷ Average hours of contact between the informal carers and the patients during their last admissions/hospitalisation as stated by the participants themselves.

²⁸ The rationale for the 2nd interview sets being one year apart is explained in Chapter 4.

²⁹ The rationale for the 3rd interview sets being one year apart are explained in Chapter 4.

³⁰ Minimal refers to help in their essential/basic needs as shopping of groceries and nothing more, as stated by the participants themselves.

	Darlene Bailey (Daughter)	57 years	same home							
3 rd	Patrick Paps (Patient)	64 years	Same home	2 times	Minimal	24 hours	2 to 8 hours	18 th August 2016		
	Wendy Paps (Wife)	64 years								
4 th 8 th	Philip Quin (Patient)	83 years	Same home	Once	Yes	24 hours	12 to 16 hours	30 th August 2016	18 th April 2017	
	Whitney Quin (Wife)	80 years								
5 th	Peter Zane (Patient)	84 years	Same home	Once	Yes	24 hours	2 to 4 hours	8 th March 2017		
	Winnie Zane (Wife)	83 years								

7 th 12 th	Paula Galle (Patient)	77 years	Not the same home	Once	Yes	1 to 2 hours	6 to 8 hours	29 th March 2017		1 st May 2018 (carer only)
	Deborah Galle (Daughter)	42 years								
9 th	Pia Hale (Patient)	81 years	Same home	Once	Yes	24 hours	3 to 5 hours	10 th April 2017		
	Hamilton Hale (Husband)	81 years								
10 th	Dawn Mason (Daughter)	61 years	Same home	Once	Yes	24 hours	12 hours	29 th April 2017 (carer only) ³¹		
	Pam Miles (Patient)	66 years	Same home	Once	Minimal	24 hours	3 to 4 hours	10 th May 2017		

³¹ The rationale why only carers were interviewed is discussed in Chapter 4.

11 th	Harley Miles (Husband)	68 years								
13 th	Danielle Lancaster (Daughter)	27 years	Same home	3 times	Yes	10 to 12 hours	3 to 5 hours			3 rd May (carer only)
14 th	Winter Lancaster (Wife)	60 years	Same home	3 times	Yes	24 hours	3 to 5 hours			5 th May 2018 (carer only)
15 th	Daphne Martins (Daughter)	51 years	Not the same home	10 times	Yes	24 hours	10 to 14 hours			26 th May 2018 (carers only)
	Dominique Martins (Daughter)	50 years								

There was a wide range of ages of informal carers from 27 years to 83 years, there was less variation in the age of the patients, who ranged from 61 to 84. There were three male and five female patients, and among the informal carers the majority were female (n=10), and the minority male (n=3). All the participants had some form of support from other members of the family or friends who were not the main informal carers, and all the informal carers had a number of hours of contact both while at home (between 2 hours to 24 hours daily) and while hospitalised (between 2 hours to 16 hours daily). However, the scope of this grounded theory study was not to have a representative population of the informal carers and their respective patients but to locate 'excellent' participants in order to obtain 'excellent' data (Morse 2007, p. 231) (see Section 4.2.1). More detailed information about the participants can be found in Appendix 22.

5.3 The social process of informal care during admission

During admission to hospital, informal care refers to the meaning the participants gave to the social process of providing informal care when patients had an acute episode relating to their heart failure and consequently were admitted to hospital. The participants gave various meanings to this social process. The below sections will address the researcher's various initial codes during coding, how these initial codes (in italics) were elevated to concepts (in bold), and how this contributed to the Hospital High Vigilance substantive theory.

5.3.1 Normality and events that affect normality

All participants started to discuss and describe their day-to-day experience of informal care and living with the chronic disease when they were at home. These day-to-day experiences were initially coded as *normality*. *Normality* was described by the participants as the act of doing normal things at home together in the context of the physical condition and limitation of the patient:

Quote 1

Darlene (daughter and carer): I usually wash her, or better, help her to wash And then she dresses up because she manages to dress up unassisted, I give her the pills and the insulin and then she stays near me in the kitchen, when she manages, because sometimes she is not well enough to stay near me in the kitchen, especially in summer. Then, I give her breakfast: in summer, she has her breakfast in the kitchen, but in winter, I give her breakfast in her bedroom because of the cold. Then she sits

on the armchair and listens to the radio because her eyesight is failing, and sometimes, she folds the clean clothes, so I stay with her until we pick up all the clothes and fold them. We normally give her the insulin at 6.30 am when I am working, and 7 am when I am off duty, and we manage like that. Because I am the one who knows what she needs, for example, insulin in the morning and the evening, and frequent meals because she has diabetes, what food to give her needs some consideration because up to two years ago she used to have bread with tomato sauce but now she cannot because she gets heartburns, so you cannot simply give her any food. I spend a lot of time with her, and near her, so I know what she needs. These are simple and basic things, but to her and to me, they matter a lot because otherwise, she will starve or else we would have to increase the Losec dose. In fact, she gets very constipated when she is in hospital, while here (at home), we give her lactulose and salads during the summer and soups and minestra in winter to help her bowel movements. I found this system that helps her prevent constipation, but at the hospital, obviously, she doesn't move, and her heart failure makes her weak and tired, unlike when she is at home where she can walk to the toilet with my help.

Quote 2

Whitney (wife and carer): So, at half-past six, I wake up because the community nurses do not have a fixed time: they might come at seven, and sometimes they come at 10.30 am or 11 am. But I make sure I am [awake] when they come, and when they ring the doorbell, I will be ready to let them in. They [community nurses] give Philip a bedbath and put him in the wheelchair, and then he comes here to the living room and watches TV. Then we go out on the front terrace because there is a fantastic open view up to Gozo, and he stays there the whole morning. Then he eats and rests a bit by putting a pillow behind his wheelchair because I cannot get him to the bed alone. Therefore, I place a cushion behind his head near the wall, and he sleeps a bit. Usually, one of our children comes to mobilise him a bit. In the evening, he goes on the terrace again, especially in summer, and stays there till 8 pm, at which point he would go back inside the house to watch the news. Sometimes when the weather is good, we stay on the terrace until 10 pm; the view is breath-taking, and you can see all the coast road and, in the evening, it is wonderful.

Normality was seen as not only doing simple tasks like cooking together; all the participants highly valued the simple act of being together. The participants tried to abide by the normal social norms of being a couple (husband/wife, father/daughter, mother/daughter) which were described as being together and doing things together. This evoked stability and control in their life, and chronic disease was not seen as a disabling factor. However, eight participants compared

their lifestyle before the onset of the disease with their current lifestyle. They all seemed to be missing their previous lifestyle of liberty and social activities. Yet, paradoxically, all the participants valued and cherished the current lifestyle because they saw their relatives as individuals rather than focusing on the chronic illness only.

Winnie (wife and carer): I go out for mass and shopping, but that's it; I stay all day here at home. Yesterday, my son called because he was very keen to take us out for a car ride, but I told him that this is not a good time to go out because the cold might make his father's condition worse and something could happen to him. My son tells me, 'But you are always there at home', and I tell him, 'So what, my dear? I am happy to spend days indoors, as long as I am with your father.'

The participants denied that their chronic condition was perceived as sickness or a disabling factor. They tried to keep the chronic illness from being the sole focus of their life. In other words, the informal carers do not reconstruct their relatives' condition as wrong but reconstruct their normality and identities as individuals taking care of their relatives with a chronic illness. This could be seen as a coping mechanism and an act to balance their lifestyle by having a high sense of control over the chronic disease. This showed that, while their condition impacted their lifestyle, the participants knew that overthinking the chronic disease could hinder their happiness. *Adapting to the chronic lifestyle* and the *changing circumstances* could induce happiness.

Pia (wife and patient): Let me tell you: he [her husband] doesn't even know how to cook basic food. He's constantly calling me because he cannot do any cooking on his own. So you can imagine: me limping along with my walking frame because I have trouble walking and going to the kitchen, peeling and fixing the pot. But then he (her husband) takes care of it because I cannot stand on my feet for long because I am afraid that I will fall on the cooker. In the morning, I take the pills myself...I manage that aspect, but he brings me some tea; I drink it and ask him to shop. He does the shopping himself, and when he comes back, I go with him to the kitchen, and we start preparing the meal. I peel an onion or a potato or do whatever is needed. I am still the chef because whatever I say is done [she laughs, and her expression looks happy]

The above quotes describe how the participants learned to live with the normality of a chronic life and about its limitations and how they adapted. This is because

the patients and their respective informal carers have lived with the CHF for years and value their homes as the sanctuary of their relationship.

Darlene (daughter and carer): At home, we have all the support we need, and it [her home] is comfortable. I can calmly take care of her needs at my own pace and in her own way, rather not the other way around... But at least at home, we are all gathered around her. Gathering around her at home is our source of comfort... because nothing beats your own home and environment.

In fact, the quote above describes how and why their homes were important for the participants (informal carers and their relatives). The participants' home/environment evoked a sense of stability and support, and met their basic needs, enhancing their normality. However, sometimes this normality could not be sustained because both the patients and informal carers described the onset of sudden acute symptoms as a stressful event. The patient's instability and emergency situations evoked a lot of different reactions by the participants:

Quote 1

Wendy (wife and carer): I feel very sad and frightened when I see him leaving home [to be admitted to the hospital]. It's not the first time he has been admitted to the hospital, mind you. He has been constantly in and out of the hospital these last eight years, but I still feel it. It pains me to see him going to the hospital. Because I wouldn't like him to go away to the hospital because his place is here [home], not in the hospital. But you have to go [to the hospital] eventually.

Quote 2

Peter (patient): We are always together... My place is here [home], not in the hospital.

Winnie (wife and carer): You feel it a lot because I help him and help him in everything.

Quote 3

Harley (husband and carer): Going to the hospital is not like going to a bar and taking a few drinks... I prefer her here [at home].

Quote 4

Danielle (daughter and carer): So my life actually stops when my father is hospitalised...

This act of adapting and balancing their lifestyle according to the chronic disease and normalising their life could be described as *status quo* or normality. At this stage, the initial code of normality was recoded as status quo in which normality and status quo are semantically related. The term status quo seemed more fitting in the current situation and described the social process involved. *The status quo* in this theory means that both informal carers and patients prefer the current state of affairs of balance and normality due to positive adaptation. The status quo could not be maintained because the informal carers had to go to the hospital due to the instability of the patient's condition. The *sudden onset* of the symptoms of the chronic illness, the *instability* of the patient and the *emergency situation* changed the status quo of the situation, which evoked a range of emotions as described by the above quote like sadness, frightening, and fear (fear of separation will be discussed in more detail in Section 5.5).

5.3.2 Motivations for delaying admissions

Sudden onset of chronic illness symptoms cause a medical instability of the patient's condition; thus, an emergency situation occurs; therefore, admission to a hospital for further specialised care is needed. However, during the interviews, it was noted that some participants delayed seeking help when the patient manifested acute symptoms of heart failure. This delay could be interpreted as the participants trying to maintain the balance and normality of the situation by maintaining the status quo. Various reasons were identified which could have led to this delay. The delay in going to the hospital could mean that the condition worsens to the point of increasing the patients' risk of mortality.

One reason for delaying admissions could be the range of emotions experienced by the participants, which could hinder the informal carer's judgement, like fear of separation.³² However, other reasons were identified in the data that could explain this delay:

Whitney (wife and carer): My husband hates being admitted to the hospital, he really hates it. Every time we need to go to the hospital because of a fainting episode or anything else, he tells

³²Fear of separation was indeed one of the main factors that were commonly mentioned by most of the participants. The fear of not being together led to other consequences and from memoing and re-diagramming, it was decided that fear of separation will be discussed in more detail in other sections of the Hospital High Vigilance theory. (see section 5.5)

me, 'Please, please do not take me to the hospital, do not send me to the hospital.. But there were times when we needed to take him, you see? He used to tell me, 'Because I will remain there, I will remain there, I will remain there, if I go, I will not leave the hospital.' Then, I used to tell him, 'But it is for your own good,' but he was never happy...

The above quote suggests that the patient refused to go to the hospital, which placed his informal carer in an awkward position of not going against her relative's wish. Eventually, this hindered the informal carer's judgement and decision-making process, resulting in a delay in the patient getting care in the hospital. This refusal to go to the hospital, resulting in a delay in seeking help, was reported with six other participants. Other motivations were identified in the data that motivated a delay in admission, which were a delay from their family doctor to visit their relative, hope that the patient's symptoms could improve, concerns about the long waiting time in the emergency department and the stressful and often cumbersome admission procedures for both patient and their informal carers.³³

The above motivations for delaying care could be explained by both the patient and informal carers seeing the current state of affairs (*status quo*) as superior to the available alternatives (admission due to fear of death expressed by the patient, as seen by the quote above). The home was perceived as a safer option, a sanctuary and normalisation of their lifestyle (see Section 5.3.1). Another reason could be a fear of regret in making the wrong decision, which was either getting the patient to the hospital and a possibility of death or further complications, or staying at home and risking the patient deteriorating or even dying, which could have biased the informal carer's judgement. Getting the patient hospitalised was rarely certain because hospitalisation may bring death and infections, which were fears expressed by the patient in the above quote and based on past experiences of both informal carers and patients (see Section 5.5.5). Delaying care to maintain the *status quo* in an emergency situation like sudden onset of the symptoms and patient instability could be explained as *status*

³³ Stressful and cumbersome because most of the time during the admission procedures the patient will be seen by healthcare professionals who do not know the patient and their informal carer well, so there is fear that the HCP will miss something. Furthermore, since the HCP does not know the patient, sometimes the informal carers are not recognised or are ignored. The notion of not being recognised as the informal carer will be discussed further in Section 5.5.1.3

quo bias. Therefore, *status quo bias* in this thesis refers to the participants' motivation to delay formal care, which evoked a range of emotions.

5.3.3 Disrupting and regaining of normality

The patient's instability challenges the status quo due to the sudden onset of the chronic symptoms of CHF. The status quo bias leads to a delay in care, and consequently, an emergency situation results from this delay that could lead to the patient's death. Eventually, this disruption in the status quo results in hospital admission and thus a disruption of the normality and/or the routine of both the informal carer and the patient. Various participants differentiated between an emergency admission and a planned admission. In fact, when participants were asked to distinguish between an emergency admission and a planned admission, a participant stated:

Darlene (daughter and carer): Because you are not in your usual environment. It's totally different from being admitted for an elective operation. You will be prepared for the elective admission; you take a bag with you, and you know that you'll be spending a couple of days or a week in hospital... everything would be planned. But patients suffering from heart problems are admitted in emergency circumstances without being prepared. You would be taking part in your normal routine, and suddenly you must go to the hospital.

The above quote shows that the informal carer's experience with a sudden hospital admission of their relatives was traumatic compared to a planned admission. Participants differentiated between an emergency admission and a planned admission. Emergency admission resulted in a state of panic due to instability of the patient, anxiety due to lack of planning, fear of the unknown due to the sudden onset of the patient's symptoms. In fact, Darlene stated:

Whenever she is in an acute phase, I am really anxious because I think that she [her mother] is going to die... because you feel really hopeless and you have to thank them [hospital staff] even though you feel hopeless.

On the other hand, discharging from the hospital evoked different reactions from the participants:

Darlene (daughter and carer): Whenever they [hospital staff] tell me that she has been discharged, I say, 'Bring her back home as soon as possible so that we can settle back into our normal routine at home.'

Therefore, discharge evoked a sense of calmness and feeling better as the participants were eager to re-establish the status quo that was maintaining normality and to balance their lifestyle again. Even though most of the participants experienced numerous admissions in the past, panic, anxiety, and fear were always present in every emergency admission.

Darlene (daughter and carer): Here at home, I have everything under control, while there [at the hospital] you lose everything because there you have nothing, there you are in their hands [hospital staff], that's it!

These feelings could be co-constructed as shifting the locus of control from internal to external. As seen in Section 5.3.1 and in the above quote, the informal carers saw their status quo as a means of controlling the situation. When the participants were at their home, there was an internal locus of control. In contrast, the participants were expected to maintain normality and balance their lifestyle to attribute their own efforts and abilities (see Section 5.3.1). Conversely, when there was an admission, there was a shift from an internal locus of control to an external locus of control in which informal carers handed over the recovery of their relatives to the care of the healthcare team. This shift to the external locus of control evoked a sense of anxiety and hopelessness, as indicated by the above quotes. Therefore, when the patients had an acute and sudden episode of their chronic illness and had to be admitted (going in) to the hospital, the informal carer's control on the situation shifted to an external locus of control. When the patients were stabilised and could be discharged (going out) from the hospital, the informal carer's control on the situation shifted to an internal locus of control. Therefore, this lack or loss of control is seen as shifting control from the informal carers to the hospital staff. This *lack of control* was evoked by various reasons, which will be expanded in the next sections (5.4 and 5.5). However, not all participants were able to shift back to the internal locus of control immediately after discharge:

Danielle (daughter and carer): I would rather have him here [home], but especially in the first three weeks [after discharge], I always feel on edge that something will go wrong. So again, I used to phone him all the time and ask him, 'Is everything ok? Do you need anything? Are you in pain?' That's the situation during the first three weeks, and then the situation gradually calms down.

Although all the participants expressed the wish to have their relatives back home as soon as possible, some participants experienced a sense of anxiety even when their relatives were at home. Two informal carers expressed that something serious or complications could have happened to their relatives while at home soon after discharge. However, most informal carers (n=11) were eager to get their relatives home as quickly as possible and felt at ease and calmer when their relatives were discharged. This difference could be explained because different participants had different meanings for the situation they experienced. The two informal carers who experienced anxiety even after discharge were healthcare professionals and, due to their past experiences, knew what could happen to their relatives. Therefore, this could explain the different views and feelings that they experienced. The notion of previous experiences will be expanded in Section 5.5.

The quotes in the above section (5.3) showed how participants (both informal carers and patients) were trying to maintain normality by adapting to the chronic illness while staying at home, which was conceptualised and recoded as status quo bias. When a sudden onset of acute symptoms of CHF occurred, the informal carers had no option but to go to the hospital for an admission (going in), which resulted in a shift in the locus of control. When the patient was discharged (going out), the informal carers again regained control of the situation. They established the status quo back home by re-normalising their chronic lifestyle by adapting again to the chronic life at home. This disruption of normality was conceptualised as a **break-in-life trajectory**.

Deborah (daughter and carer): Let me tell you what I think happened. She was stable, and when she was admitted, she was so unstable that I thought she would not make it this time... And I remember telling my sister while we were going home after spending a night at the emergency department that this time, she would surely not make it.

In the break-in-life trajectory category, the participants described how an emergency situation provided by a sudden onset of the CHF acute symptoms and the unstable condition of the patient evoked a range of emotions to the informal carers – anxiety, despair, loneliness, fear of the unknown, fear of death and guilt. These feelings were conceptualised as *emotional turmoil*, which encapsulates all the participants' emotions during the admission of their relatives suffering from CHF.

Winter (wife and carer): When they [hospital staff] tell you that he [her husband] has something wrong in his heart, I was shocked because I never expected it. When he was admitted, I used to be near him all the time because he would constantly be on your mind, and you would always be thinking, 'What is happening? What is going to happen?' You wouldn't know what might happen and you wait...

Consequently, the patient's emotional turmoil and instability, the emergency situation, and the sudden onset of the symptoms provoked by an acute episode of the chronic illness induces a status quo bias, which causes a break-in-life trajectory. From the quotes presented in this section, a break-in-life trajectory evoked a *constant watchfulness, lack of control, watchful waiting, and presence* of the informal carer, as explained in the above quote. These initial labels were coded when the participants described admission, and the central meaning given to these codes together was **vigilance**. Vigilance refers to a careful watch for possible dangers and difficulties that could happen during admission and hospitalisation of their relatives. The category 'vigilance' will be expanded on in Section 5.6.

5.3.4 Summary of the social process of informal care during admission

In the first section of the Hospital High Vigilance theory, a break-in-life trajectory was seen as one of the main overarching categories explaining what could be happening to informal care during admission. The effect of disruption of the status quo and shift in the locus of control during the admission and discharge was co-constructed as a break-in-life trajectory. The break-in-life trajectory affected the relationship between the informal carer and patient (which will be expanded in Section 5.4). Consequently, a status quo bias is one in which the instability of the patient's condition, the sudden onset of the symptoms and the emergency situation evoked a sense of striving towards status quo, which resulted in a high vigilance state of the patient by the informal carers to prevent harm to their relatives. However, another explanation for the above could be that the informal carers dreaded the separation that would occur during admission, which will be expanded in Section 5.5.2. Further to this, a break-in-life trajectory changed the relationship between the informal carer and the patient during hospitalisation, which will be discussed in Sections 5.4 and 5.4.4.

5.4 The meaning and importance of informal carers for patients with CHF

This section will expand and discuss the meaning and importance of informal carers for patients with CHF during admission and hospitalisation. In the previous section, the social process of admission during an emergency situation and a sudden onset of the chronic illness was conceptualised as a break-in-life trajectory. This evoked a range of emotions which was conceptualised as emotional turmoil. However, this emotional turmoil could have been evoked because of the relationship between the participants (patients and informal carers). Participants (patients) valued the relationship they had with the informal carers. They described how they relied on informal carers, supported each other, and complemented each other when they were home and while the patient was hospitalised. The below sections will start by stating and giving meaning to the relationship between informal carers and patients based on a long-standing relationship. Then, an explanation will be given to the meaning and importance of informal care for patients with CHF, which evolved and changed during admission and hospitalisation.

5.4.1 Relationship between informal carers and patients

This relationship was considered extremely important to all participants (patients and informal carers) involved in this study. It was built and based on years of knowing each other and living together (from a minimum of 20 years to a maximum of 62 years). The relationships noted in the interviews go beyond knowing and living with each other.

Darlene (daughter and carer): It's a mother–daughter relationship, you know? Even when we argue – because we are similar, of a similar character – a strong sense of family prevails because I am always here... because when I got married, I didn't go to live in another house but continued to live here with her after I got married and therefore we are like one family, it is not as you come once a week to see her, I am always here. It's not like when she was in the hospital when I used to go to see her and then leave. I am always here near her, washing her clothes and washing her... since we live together, we are together all the time, and near each other, so I feel she's part of me, you know?

The participants described a normal relationship between a close family member (in this case, between the informal carer and the patient). However, the quote above highlighted that her mother was part of her as *one being* entity (“*I feel she's part of me*”). The participants described their relationship with their patients as

being symbiotic. This is because participants frequently identified themselves as being one with their relatives by using the word “we” as an expression of describing what is happening, e.g., “**WE** never wear a nappy” (*Darlene – daughter and carer*), or “**WE** are there (hospital) to be treated” (*Deborah – daughter and carer*). All the participants expressed emotional turmoil, feelings like loneliness and vulnerability, when their relatives were hospitalised. This showed that the relationship between the informal carers and patients was symbiotic, where they were interdependent and *relied on each other*. Although the informal carers’ importance for the patient was obvious, there was more than that, as shown by the participants themselves. The participants described rituals of not wearing a nappy, feeding them, washing them, and being near them, which were developed through years of being together. These rituals reflected a family’s sense of itself. This family sense of itself could not be changed or stopped when the patient was admitted to hospital.

Quote 1

Dawn (daughter and carer): We were always close, even because before I used to live in another place up the road, but I was always here, always coming and going, coming and going... until my husband came from work, I always used to be here [her mother’s house and] then I go home [smiling].

Quote 2

Wendy (wife and carer): I have one thing to say: marriage is for the good and the bad. When he was in good health, we did enjoy ourselves together, and now he is sick.

Quote 3

Dawn (daughter and carer): I received a lot of help and support from her, even when my husband died – because my husband died very suddenly, he was not ill or anything... he suffered a stroke during the night. He died in only ten days, but I really appreciate the support she gave me during that time.

Furthermore, participants (informal carers) were not seeing themselves as having a separate identity from their relatives. Still, they were constantly examining themselves within the context of their relationship with their relatives by using the terms ‘we wear a nappy’ or ‘we are there (hospital) to be treated’. In actual fact, the informal carers did not wear a nappy or did not need to be treated (the patient required the nappy and the treatment). Therefore, the informal carers and

patients were not independent identities, and they were forming and reforming themselves within each unique relational context; their relationship had a specific identity. The participants had a familial goal (getting better so they can be discharged) which took precedence over the informal carer's individual goals, which will be explained further in this section. Therefore, the relationship between informal carers and their relatives could be defined as a **sybiotic relationship**. The **sybiotic relationship** means that both the carers and patients identify themselves as one being that benefits from each other based on needs, *long-term relationship*, and *intimate interaction*.

Quote 1

Patrick (patient): Otherwise, I'm hopeless. God forbid she [carer] wasn't around. Her presence really helps me.

Quote 2

Pamela (patient): He [husband] is my life [here she gets emotional].

Quote 3

Pamela (patient): Because I have to guide him, even in his personal things, even financially, food, clothing ... in everything ..., in fact when he used to come near me in hospital and I would guide him what to do.

From the data (see above quotes), the patients mainly benefited because their informal carers gave them physical and emotional help (the above quotes will be expanded more in Sections 5.4.3, 5.4.4). However, informal carers benefit primarily from emotional support from the patients and sometimes even guidance in their personal life (Section 5.4.2 will discuss this in more detail). This could be derived from years of living together and knowing each other (see Section 5.2 and Appendix 22). In other words, the sybiotic relationship explained the benefit that both informal carers and patients have by this relationship based on intimate interaction and a *long-term basis*. Therefore, both informal carers and their relatives (patients) took responsibility for each other and depended on each other. The informal carers invested a lot of time and effort in this relationship. Still, they reviewed their reward from the sense of *acceptance, support and companionship* (as seen in the above quotes). Furthermore, this time and effort that the participants invested were based on the past when their relatives (patients)

showed respect during their long-standing relationship (see quotes above and in Sections 5.4.3, 5.4.4). Therefore, in time of crisis (a break-in-life trajectory) the informal carer considered the past long-standing relationship more important than their self-interest.

After examining and discussing the relationship between the informal carers and patients, it is vital to investigate how this relationship changed or was affected during admission and hospitalisation. The sudden onset of acute CHF symptoms that resulted in admission had a straining effect on the relationship between the informal carers and the patient. Therefore, examining the needs³⁴ of the informal carers and patients could bring light to what changed during admission and hospitalisation.

5.4.2 Physiological/basic needs

Physiological/basic needs refer to the individual's need to eat, drink, breathe, be warm and rest (Maslow 1954). These physical needs are essential to survive.

Pamela (patient): While in hospital, he used to come near me every morning to wash me, brush my hair, chat with me, and then when the food arrived, he used to feed me because I couldn't use my arms, I couldn't lift them and couldn't even move my head I couldn't move, and I couldn't get down from the bed. And he even used to give me something to drink.

As seen in Section 5.3.1 and the above quote, the patient's basic needs were always met at home and during hospitalisation. The above speaker and four other patient participants stated that although they were hospitalised, they looked forward to attending to their daily needs. Not because the healthcare workers did not do their job, but because the patients looked forward to the presence of their informal carer near them. This highlighted the importance that informal carers had for their relatives (patients) to satisfy their basic needs even while hospitalised. However, this was not the case for the informal carers when their relatives were admitted and hospitalised:

Quote 1

³⁴ These needs will be examined and compared to Maslow's hierarchy of needs, further discussion of which will be done in Chapter 6.

Pamela (patient): Because I have to guide him, even in his personal things, even financially, food, clothing... in everything ..., in fact when he used to come near me in hospital and I would guide him what to do.

Quote 2

Pia (patient): Because let me tell you: he does nothing on his own, not even cook something basic.

Quote 3

Danielle (daughter and carer): Yes, it is true because my life revolves around caring for my father, and it is true that I depend a lot on him. Every time something breaks down at home, I tell Dad, 'Look, this happened.' When he was hospitalised, I couldn't tell my dad. ... when he was in the hospital, I couldn't ask him, you know? I really depend on my dad a lot, and I know that this is not good, but yes, I rely immensely on him... so you do feel his absence when he's hospitalised.

Further to the above quotes, various participants stated that most of the time, they did not have time to eat or did not eat at all, while some of the participants tried to stay near the patient on an armchair and did not sleep at all.

Danielle (daughter and carer): In my case, I didn't want to eat; I didn't want to go out. I used to cry all the time and worry all the time [while her father was hospitalised].

Therefore, during admission and hospitalisation, the informal carer's basic needs were not always met. However, there was a collaboration between the informal carers and the patient through the symbiotic relationship that existed. While the patients were helped with their basic needs by the informal carers and/or the hospital staff, the patient himself instructed or tried to help the informal carer with their needs during hospitalisation. However, the unmet basic needs led the informal carer into survival mode. Signs of survival mode were seen in the data. In contrast, most of the participants experienced not only sleep disruption and not eating (as seen in the above quote) but constant anxiety when the informal carers were not near their relatives (see Sections 5.3, 5.5, and 5.6). The informal carers were trying to cope with the situation to help or watch over their relatives or prevent them from harm. Furthermore, the above quotes highlighted the vulnerability of the informal carers in which they depended for their basic needs on the patient even when the patient was admitted and hospitalised.

5.4.3 Safety needs

The next need identified was the safety needs of the informal carers and the patients. The relationship (symbiotic relationship - Section 5.4.1) between the informal carers and patients derived from the safety of a long-term relationship and the sense of being one entity that relied on trust and each other. The instability of the patients' condition that required emergency admission and thus hospitalisation (a break-in-life trajectory) and consequently separation from each other (see Section 5.5) provoked various reactions from the participants:

Quote 1

Patrick (patient): Otherwise, I'm hopeless. God forbid she [carer] wasn't around. Her presence really helps me.

Quote 2

Dominique (daughter and carer): Yes, my father would want my sister and me to stay near him all the time. It's like our presence calms him down and puts his mind at rest.

Quote 3

Hamilton (husband and carer): I used to be depressed..., that I am here [home] alone, you know? Until 8 or 8.30 pm there is always someone [of his children] with me, but then the time would come for them to go home, and I used to miss her [his wife] a lot because I would remain here [home] alone, and I wouldn't have anyone to talk to.

Participants (both the informal carers and the patients) expressed their vulnerability when they were apart and experienced emotional turmoil (depression and anxiety). On the other hand, when they were near each other while hospitalised, all the participants felt a feeling of calmness (see quotes 1 and 2 above, and quotes in Section 5.4.1). This showed that the mere presence of informal carers near their relatives (patients) was beneficial for both the participants. Therefore, admission and hospitalisation challenged the safety of the symbiotic relationship that existed between the informal carer and the patient. A sense of safety in a relationship was important because safety was the foundation that created the ability to connect with each other, be intimate and enhance the mutual affinity and attachment between the informal carers and the patients. Furthermore, safety was challenged by the fear of death due to instability, the emergency situation, and the sudden onset of the symptoms (as

seen in Section 5.3) in which a break-in-life trajectory occurred. The participants were striving towards re-establishing the status quo in order to regain control and safety of the situation by going back to their homes and lifestyle (status quo) (see Section 5.3).

5.4.4 Love and belonging needs

The needs for love and belonging were identified in the data, in which various participants gave various meanings of what the need to be loved and to belong meant for them.

Quote 1

Patrick (patient): But having spent so many days and years together – 42 years is a lot, isn't it? I cannot live without her. I may seem dominant, but she is everything for me... my "bastun" [walking stick]. And let me tell you: I really don't like being on my own [at the hospital], even though there are nurses and other patients, but I would still miss speaking to her. Talking over the phone is not the same; I would want to see her in front of me. Her presence really helps me.

Quote 2

Pamela (patient): He is my life [here she gets emotional].

Quote 3

Harry (husband and carer): She is 'l-ghoqda tieghi' [my knot].

Interviewer: What do you mean by your knot?

Harry (husband and carer): She is my biggest friend, she is everything for me, she is my life.

The participants often used strong words or Maltese metaphors to explain and give meaning to their relationship. Patrick defined his wife and informal carer as the 'bastun' of their relationship, which means being like a walking stick for him. He mentioned his wife as being his 'stick' 3 more times during the interview and even started to cry when he said she could die before. Meanwhile, Harry described his relationship with his partner as 'l-ghoqda tieghi', a Maltese phrase meaning a powerful bond like a knot. These Maltese metaphors have a strong meaning when used to describe someone. Other participants continued to state their informal carers are not only their biggest friends but their everything and their life. This showed that the informal carers shared intangible support with their

relatives (patients) such as social and emotional support, love, friendship, and appreciation, making this relationship valuable to them.

The emergency situation and admission and thus a break-in-life trajectory provoked a sense of loneliness and *vulnerability* from the participant, which could be derived from the fear of losing the love and belonging of their symbiotic relationship. Thus, they increased their vigilant stance by staying near the patient for long hours, phoning, and always thinking about them, as seen in Section 5.5 and Section 5.6. Furthermore, less contact time between the informal carers and patient due to hospital policies and personal commitments decreased the intimacy of the relationship. Apart from the patient's vulnerability and the emergency situation that caused a break-in-life trajectory which affected the relationship between the informal carers and the patient, other issues were noted, hinted at in the above data, mainly the separation. This will be further discussed in the next section.

Therefore, the next part of the theory evolved around the symbiotic relationship between the informal carers and their relatives (patients). This symbiotic relationship was based on a long-term basis, one being, intimate interaction, relying on each other, acceptance, support, companionship and trust. These were based on the needs of informal carers and relatives (patients) and their ability to maintain the status quo and resilience (which will be explained in Section 5.5). Thus, a break in the symbiotic relationship occurred when admission and hospitalisation occurred due to the worsening of the patient's chronic symptoms. Consequently, the informal carers experienced the loss of control of the care of their relatives due to the experiences of unmet needs, thus increasing their vigilance state. This will be expanded in the following sections.

5.5 The social process of informal care during hospitalisation

The following section will reflect on the participants' accounts and meaning of how organisational and practical issues during hospitalisation intruded and affected the informal carers. The above sections described how a symbiotic relationship and status quo enhanced the ability to cope with the chronic disease and, hence, the informal carers' resilience. The support that the informal carers and patients received from each other (whether emotional, physical or psychological) derived from the meaningful relationship (symbiotic relationship)

described above. Nearly all the informal carers had additional social support: other family members and/or friends that offered support and communication not only while hospitalised but even at home (see Table 8 in Section 5.2).

As seen in the data, this social support from other family members and/or friends consisted of respite (taking care of their patient so that the informal carer had time for themselves), helping in their day-to-day chores, emotional support and community services. This support helped the informal carer in trying to be *resilient*. While at home, they could cope and bounce back because, as described in the previous sections, the home was their sanctuary. Furthermore, the informal carers had control over the situation, their relationship with the patient was not under threat, and the patient's condition was stable. However, informal carers showed other qualities which could be attributed to being resilient.³⁵

Quote 1

Dominique (daughter and carer): My dad had been sick for a long time, and we are with him all the time... I think I almost got used to everything, and the experience with him helped me so much that sometimes I feel that I know more than a doctor (laughing).

Quote 2

Wendy (wife and carer): Friends ask me if I don't need anything and so on. So far, I have managed on my own; my son helps me too. For example, if I need somewhere to shop, my husband [the patient] takes me by car. If I have a long shopping list, I go to the supermarket by public transport, and then he tells me to phone him when I am at the counter about to pay. Because in the past he used to stay with me while shopping but now he is not strong enough to stay with me. But until now, with the help of God, I always found support from someone.

Quote 3

Deborah (daughter and carer): Looking back, it [admission and hospitalisation] was a very good experience because in those four weeks that she spent in the hospital, my mum regained her health. So, on the whole, when you look back, you say it was a blessing that she was hospitalised, even though I was thinking that she was going to die, and I was going mad...

³⁵ The idea of resilience here is based on the Kobiske and Bekhet (2018) conceptualisation of resilience which will be discussed in Chapter 6.

Quote 4

Darlene (daughter and carer): Once they assigned a carer from the Hospice Movement for my mum when we couldn't do otherwise, but then after a while, as a family, we organised ourselves and cancelled the help from the carer.

Quote 5

Harley (husband and carer): I leave everything in God's hands, you know?

From the quotes presented above and quotes presented in this chapter, one can notice various attributes of resilience that helped the informal carers adapt to the adverse situation of chronic illness and the instability of the condition. *Resilience* in this context can be described as a dynamic process built after years of living with chronic disease and the relationship between the informal carers and the patients to overcome adversities while at home. For this study, resilience meant having attributes of self-efficacy, flexibility, problem-solving, and spirituality. Therefore, being resilient meant being flexible in the informal carers' thoughts and actions, which helped them adapt to everyday life challenges. This was seen frequently in the data, where some participants changed their lifestyle entirely to help their relatives.³⁶ The participants (informal carers) adapted to their new normal day-to-day lifestyle while caring for their relatives with CHF while at home. Most informal carers were positive in their thinking and thus had an optimistic attitude even during challenging situations. Quote three above clearly states that although the informal carer was in great distress during her mother's hospitalisation, she still found the positive side of the situation.

This positive attitude did not diminish the pain or anxiety they suffered when they saw their relatives in an unstable condition. However, all the participants were convinced and believed that they could care for their relatives while stable at home. Therefore, being self-efficient allowed the informal carers to remain strong. Data presented above and in the rest of this chapter shows how resourceful the informal carers were in solving problems and overcoming challenging situations. The informal carers showed a high sense of independence in their actions and

³⁶ Harry stopped taking care of himself in order to be near Pamela during hospitalisation. Darlene and Danielle changed their working routine in order to be near Patricia. Wendy, Whitney, Winne, Hamilton, Dawn, Harley, Danielle, Daphne and Dominique stopped attending social activities. Daphne and Dominique stopped working.

thoughts. While all the participants had access to the community services, only some participants (four patients) used them. Most of the participants (five informal carers) often reverted to praying or meditation to help them find meaning in life events. This faith in higher powers often provided comfort but did not mean that everything would turn out well; in fact, all the participants acknowledged fear of death.

However, the flexibility was compromised and somewhat challenged when the patient had to be admitted and hospitalised, which affected the symbiotic relationship between the informal carer and patient. The sense of self-efficacy of the informal carers was challenged by the worsening of the chronic symptoms, which resulted in hospital admission. Thus a break in the symbiotic relationship was noted. Most participants had negative thoughts because they feared losing their relatives during admission and hospitalisation, thus affecting their symbiotic relationship. Furthermore, admission and hospitalisation impacted the resourcefulness of the informal carers. While the patient had worsening symptoms, the informal carers used all the resources they had in their hands (GP, friends, private clinics, health centres) but could not avoid admission and hospitalisation. Moreover, praying by the informal carers and, therefore, spirituality was more evident when the patient was admitted and hospitalised. Thus, issues were identified during the interviews which affected the informal carers' normal resilience. Resilience was based on their symbiotic relationship; however, exacerbation, admission, and hospitalisation provoked a break in the symbiotic relationship, which affected their resilience. The following section will explain what barriers or issues provoked *a break in the normal resilience* of the informal carers and their reaction to this.

5.5.1 Factors affecting resilience

As discussed in the above sections, the informal carers showed a great deal of positive resilience. At the same time, the patient was at home in a status quo situation and a stable condition. Positive resilience meant that the participants showed a positive attitude to adapt to an adverse situation such as chronic illness and instability rather than a negative attitude. However, when exacerbation of the chronic symptoms manifested, admission and hospitalisation affected the symbiotic relationship. Thus, various factors were noted in the data that affected the normal resilience of informal carers and consequently their care of the patient.

5.5.1.1 Difficulties in gaining access (near the patient)

Difficulties in gaining access (near the patient) involved difficulties that informal carers encountered to be near their relatives in order to be able to care for them or watch over them while their relatives were hospitalised. The participants (both informal carers and patients) co-constructed the meaning of gaining access by challenges that prevented informal carers from spending time with the patient. These challenges changed how the informal carers and the patients interacted with each other. Thus, this challenged the symbiotic relationship between the informal carer and the patient and their resilience. As demonstrated in Table 8 in Section 5.2, all the informal carers spent long hours with their relatives when they were admitted into hospital (from 2 hours up to 16 hours). However, being physically near the patient did not mean it was an easy task for the informal carers. Different participants described different challenges and factors that hindered them in spending time with the patient while hospitalised.

Quote 1

Harry (husband and carer): Parking was a problem. Finding a parking place was impossible. It was a huge hassle every time, and on various occasions, I had to park far away, and I couldn't walk that much because I had just undergone surgery on my leg.

Quote 2

Winter (wife and carer): I definitely wasted a lot of time waiting for buses and commuting, especially with the hospital bus schedule being what it is... if you miss one bus, you have to wait for a long time until the next bus arrives. This was quite a problem for me.

One of the challenges that the informal carers encountered was physical barriers that prevented the informal carers from being with the patient. The physical barriers consisted mainly of parking problems on the hospital grounds or inefficient public transport. The consequences of these physical barriers were various. One participant (Harry) developed a leg ulcer because of the long-distance he walked due to parking far away from the hospital. He did not tell Pamela (his wife) about this while hospitalised, not to worry her. As soon as Pamela was discharged, Harry was admitted for treatment for his leg ulcer, but he waited for Pamela to be discharged before he sought help. This showed what sacrifices the informal carers underwent to spend more time near the patient. In

fact, most informal carers spent a lot of time near the patient when they were hospitalised to help with their needs.

Although healthcare professionals surrounded the patients, the informal carers preferred to watch over and help them instead of leaving them in the hands of the hospital staff. This suggests a sense of overprotection from the informal carers, which led them to spend lots of hours near patients/relatives and thus ignore their own basic needs. Therefore, going around the hospital grounds to search for parking or using public transport was interpreted as losing precious time they could spend being near their relatives (patients). A common factor that was noted in the interviews was wasting time. This anxiety of wasting time searching for parking or using public transport prevented the participants from being with the patient. However, it could be derived from a more profound notion that informal carers value their time with relatives (patients). Thus, searching for parking or using public transport affected their contact time with their relatives and their relationship. Furthermore, physical barriers impacted the informal carers' flexibility, self-efficacy, and resourcefulness. Self-efficacy was impacted because less time near their patients affected their confidence in taking care of their relatives. This was compensated by informal carers washing the patient or feeding the patient instead of leaving these tasks to the hospital staff. Flexibility was impacted because the participants had problems of parking, or because of inefficiency of the public transport, they were having difficulty in adapting to the new situation (hospitalisation). Therefore, by ignoring their basic needs, the informal carers increased their flexibility to be near their relatives more and watch over them. Although informal carers went out of their way to overcome the difficulties of seeing their relatives, in some instances, they did not seek help from the hospital personnel. They continued to wash them and feed them even while hospitalised, making them less able to cope with the situation.

Some participants identified institutional barriers which prevented informal carers from being physically with the patient while hospitalised. The hospital environment, being an organisation, had specific rules which made it more difficult for the informal carers to spend time with the patient and therefore affected their informal carer duties, relationship and resilience.

Danielle (daughter and carer): It felt like I was wasting my time; for example, I would be at home, and I would say to myself, 'I'd

rather be near him,' but I know that it's not possible, you know? I know it's not my fault, but at that point, I would feel as if I was wasting time. All the time, I would anxiously wait for the time to go see my father at the hospital to arrive.

One of the institutional barriers consisted of fixed visiting hours imposed by the hospital on the informal carers. A fixed visiting hour impacted the ability of the informal carers to be near their relatives, in which they felt that by not being near their relatives, they were not taking care of them. Like physical barriers, the notion of wasting time and not being with their relatives was evident when asked about the visiting hours. However, the informal carers stated:

Quote 1

Darlene (daughter and carer): Extended visiting hours are definitely helpful, especially for my brother and sisters, but since I work there (at the hospital), I could go during my break, you know.

Quote 2

Harry (husband and carer): Whenever I went [to the hospital] they [hospital staff] used to always allow me to be near her [Pamela], even when I went outside visiting times, because actually, I used to reduce their workload because instead of them washing her I used to do so...

Quote 3

Daphne (daughter and carer): My sister and I didn't encounter a lot of problems. We could go near him any time we wanted because my dad was hospitalised very often because of several health conditions, so we became great friends with the nurses too.

The extended visiting hours³⁷ helped the informal carers in their self-efficacy and even in their flexibility by drawing upon their social support. This was important for the participants because with the extended visiting hours someone was always there with their relatives to watch over them while hospitalised. In contrast, as seen in Danielle's quote above, although they recognised the importance of the extended visiting hours, participants felt it was still not enough. To overcome this barrier, some participants bartered their way near their relatives to spend

³⁷ The hospital implemented extended visiting hours from 2 hours a day to 5 hours a day, but still there were times (especially in the morning and during the night) that the relatives were not allowed near the patients.

more time by reducing the workload of the hospital staff by performing care themselves, talking to the nursing officers, talking to the medical consultants or making friends with the hospital staff, thus increasing their sense of self-efficacy. This bartering to be with the patients was evident in four other interviews. However, hospital routines and hospital staff attitudes were identified as other institutional barriers that affected the symbiotic relationship and the resilience of the informal carers.

Quote 1

Darlene (daughter and carer): ... I felt intrusive. That is how I felt.

Interview: you used the word 'intrusive'.

Darlene (daughter and carer): Yes, intrusive. It is like you are invading their [healthcare professionals'] world. But actually, that was not the case because all I used to do was prudently ask some questions. I wouldn't even open the file... But it feels like you have forced your entry...

Quote 2

Deborah (daughter and carer): When my mother was in the hospital, to be able to talk to a doctor. First, they (hospital staff) ask who the patient is, then they would tell you 'Let me see who her allocated nurse is.' Then, the nurse would often not be available because she is bed-bathing other patients. So even talking to them (hospital staff) over the phone is a struggle. It was definitely a struggle. Then they would tell you, 'Her nurse is not available right now; she is with the patients, phone after 9.30.' When you phoned after 9.30, they couldn't find her nurse, and I thought that the ward round would soon be ready. It was hard to talk to them.

Interviewer: So it was like chasing time and constantly chasing them...

Deborah: Exactly, and I used to say that I will not be able to talk to the consultant because he will be ready from the ward round. Then when I phoned at 9.30, they (hospital staff) told me that her nurse was not there, then they asked the nursing officer. They told me that the nursing officer was busy on the phone and that I was to phone later, maaaaaa.

The word 'intrusive' was a strong word used by the participants while they were visiting their relatives while hospitalised. This meant that the participants felt they were outsiders and found it difficult to be near their relatives. The sense of intrusiveness could derive from the fact that the informal carers were unfamiliar

with the hospital environment. However, some participants had regular visits for appointments or readmissions due to the patient's condition. Furthermore, some participants (Darlene, Danielle and Deborah) were healthcare professionals, and therefore one could assume that they would be accustomed to the hospital environment. However, this did not happen as all the participants felt out of place and struggled against these institutional challenges. In fact, some participants (see Deborah's quote above) explained how a simple task of information-seeking by the informal carer from the healthcare professional resulted in a struggle and sense of frustration. Therefore, institutional barriers impacted the normal resilience of the informal carers by diminishing the self-efficacy, resourcefulness and flexibility of the informal carers.

Personal commitments were identified by the informal carers that prevented them from being with their relatives. These personal commitments involved informal carers' social activities, work, housework and taking care of other family members. Although these personal commitments were present even when the patient was at home (status quo), hospitalisation made it more difficult for the participants to be with the patient and take care of them. Participants elaborated on this, which hindered them from being near their relatives while hospitalised:

Darlene (daughter and carer): You cannot always go near her [mother while hospitalised] because I do not have only her [Patricia] in my life. I have my work, and sometimes I have to care for my granddaughter, and you get caught in the middle. I would prefer her to be here at home because her home is very close to my house. And when I am at work, I cannot go all the time. I only used to go during my break at noon to bring her food.

The participants' (informal carers') lifestyle and other commitments prevented them from being with their relatives while hospitalised and thus from gaining access to their relatives. Most of the participants preferred their relatives at home near them instead and thus striving towards the status quo, than in hospital.

Quote 1

Winter (wife and carer): ...I was employed at that time, and therefore I had to go to work, but he [her husband] was constantly in my thoughts. I had to go near him at the hospital nearly every day after work, so most of the time, I was near him rather than at home. Certain things stopped; for example, I practically abandoned housework. We used to rush home, eat a piece of bread in a hurry and go near him. This is a must because

of the fixed visiting hours and your work commitments, so you have to catch the bus at a specific time. You must do what it takes.

Quote 2

Danielle (daughter and carer): At that time, because of my work and other commitments, I had to make adjustments. For example, I couldn't leave my ward, although sometimes I managed. For example, the last time my father was admitted, I took emergency leave, but it is not always possible. You see, there were times when I had just left my workplace to be near my father. Regarding my personal commitment, I always managed to cope somehow; for instance, I would have to cancel my planned social activities to be there [near her father].

These personal commitments put the informal carers in a problematic situation by experiencing difficulty being with the patient while hospitalised. This issue of personal commitments that could prevent the informal carers from being with their relatives while hospitalised was described by the informal carers and even acknowledged by the patients themselves. In fact, Paula stated:

Paula (patient): I really do not like to be admitted. First of all, it is not a nice thing to be hospitalised, because it means that you are very unwell or there is something serious going on. And secondly, my heart is always here at home. Also, it is a burden for my family to come and visit me.

Interviewer: Do you think that it is difficult for them to come and visit you while in the hospital?

Paula (patient): They come to visit me, don't get me wrong, but I am concerned that they have to go out of their way to do so because I know that they are very busy with their work and their children.

Not being with the patient all the time resulted in some informal carers having the following reaction:

Darlene (daughter and carer): And I think to myself: look how I ended up; I cannot take good care of her [mother].

Here, the participant expressed her frustration in not being with her mother and in blaming herself for not being able to adequately take care of her mother. This blaming of self could be interpreted as losing control of the situation and a high internal locus of control. However, this sense of blaming herself was a common factor. Other participants blamed themselves because they experienced an

episode over which they had no control, like developing a stroke during previous hospital admission and felt they hadn't done enough to prevent it as they were not with their relatives when it happened. Deborah continued to elaborate how this blaming herself affected her normal life, especially during her work:

Deborah (daughter and carer): My mother's admission affected me really badly. I was not managing to concentrate on my job. And as I am in charge here [at work] and I have certain essential roles, I was constantly apologising to the staff. I told them that I knew that I was not giving my best. I knew that my mind was not there [at work]; it is true.

Therefore, the above data shows how the participants' personal commitments prevented them from being near their relatives while hospitalised. The consequence of this was participants blaming themselves and it affecting their personal lifestyle; thus, hospitalisation affected the relationship between the informal carer and patient by a loss of control of the situation. Therefore, participants blaming themselves influenced the positive thinking of the informal carers. This is because they felt that they were not doing enough and this increased their guilt about adequate care of their relative during hospitalisation. However, informal carers described how sometimes they tried to cope and adjust their lifestyle by being more flexible (cancelling social activities or taking leave from work) to regain control and have more time near their relatives. But this affected their ability to cope by not seeking further help within their social support or ignoring their social support.

Therefore, difficulties in gaining access involved physical barriers, institutional barriers, and personal commitments, which impacted their ability to be resilient and thus, *a break in normal resilience* occurred. As seen in the above data, participants took various steps (cancelling social activities, taking leave from work, bartering to be near the patient) in an attempt to strive towards normal resilience.

Deborah (daughter and carer): You need to understand that I was worried, even though I was a bit lucky because in the morning I could be near her in the ward [the carer is a healthcare professional], and my colleagues were very understanding and used to encourage me to go near her. And in the afternoon, I knew that my sister would go near her, but I would worry during the night. The night is too long. I was concerned because my sister would leave at about 8 pm, and no one would look at her

until 8 am the following morning. She was indeed in hospital, but because she had MRSA, they [the healthcare professionals] used to go near her just to give her the treatment, that's it. She is too shy to use the buzzer. And I used to say if something happened to her, no one would notice. So, I used to worry a lot, and during the night I used to go near her till about 1 am or 2 am and I used to say the night is shorter like this because I couldn't sleep at home thinking about her. I used to feel better near her because at least I could see her with my own eyes, you know.

These difficulties in gaining access, as seen in the above quote and other quotes in this section, resulted in informal carers trying harder to be near the patient to watch over their relatives during hospitalisation. This highlights the notion of increasing presence near their relatives to avoid harm. Not being near their relatives during hospitalisation for various factors (as highlighted in the above sections) increased the constant watchfulness over their relatives and the lack of control over the care of their relatives because they were 'alone'. Although the patient was in the hospital surrounded by healthcare professionals day and night, the informal carers still felt vulnerable that something would happen to their relatives. Thus, this evoked a sense of duty to be near their relatives and resulted in a high vigilance state by the informal carers while their relatives were hospitalised.

5.5.1.2 Separation anxiety

The above section demonstrated the informal carer's difficulties in gaining access to their relatives while hospitalised and how this affected the relationship between the informal carer and the patient (less contact time), resilience, and the reaction of being vigilant to watch over their relatives. However, the informal carers eventually had to leave their relatives 'alone' while hospitalised when the patient was unstable due to the exacerbation of their chronic disease. The reactions of the informal carers when they had to leave their relatives were varied:

Quote 1

Winnie (wife and carer): Of course, you feel lonely because even when you look at the bed, you see it empty. The emptiness I used to feel while he was hospitalised was incredible. We are used to talking or arguing [laughing], but when he is in hospital, you cannot do that, you know.

Quote 2

Hamilton (husband and carer): I used to wonder when she would come back home and think to myself, 'Who knows how she is, right now?' I used to worry a lot, always thinking about her, 'How long she will stay there [in the hospital]? When is she going to be discharged? Who knows if she is in pain?' So it was like that.

Quote 3

Darlene (daughter and carer): I felt a bit lonely... I felt vulnerable because she is there [in hospital], so you feel vulnerable.

Quote 4

Whitney (wife and carer): You have no idea what it feels like. I didn't know what I was doing. I found a room and started banging my head on the wall.

This separation from the patient changed how the informal carers and the patient interacted with each other, affected their self-efficacy and challenged their symbiotic relationship. The symbiotic relationship was based on intimate interaction, acceptance, support and companionship. Therefore, the dynamics of their long-term relationship was changed, thus affecting their love and belonging needs. The need for love and belonging was interrupted due to hospital social norms, regulations and personal commitment, as seen in the above section. Consequently, informal carers ignored or disregarded other needs like biological and physiological needs (not eating, not sleeping), their safety needs (not able to connect or be intimate due to less time being together), and ignored or avoided other social interactions or social support (not going out with friends, switching off the mobile, ignoring other family members' needs and not letting the hospital staff bathe or feed the patient). This sense of *separation anxiety* was not seen while the participants were at home (status quo). Separation anxiety in this context occurs when physically the informal carers are not near their relatives. It impacted the love and belonging needs of their relationship. As seen in Sections 5.3 and 5.4, the needs of the informal carers were met, and thus their ability to be resilient was positive. Consequently, their symbiotic relationship was threatened by sudden admission and hospitalisation due to worsening chronic symptoms.

However, other evidence was seen in data that could explain the difference between separation while the patient was in a stable condition at home and separation while the relative was hospitalised. When the participants were

explicitly asked what their thoughts were about their future when they were not near their relatives while hospitalised, they answered:

Whitney (wife and carer): Yesterday is gone. You do not know what will happen tomorrow... you live for the day... life is very short... the best thing to do is to forget what happened yesterday, and nobody knows what's going to happen tomorrow... you live the day... it is the best thing to do in life... if you constantly worry about what might happen... what will happen to him... I don't want to think about that... that's the best thing to do... you live the day... I wouldn't dream of having to live without him.... So, I just don't think about it...

Interviewer: The future...

Whitney (wife and carer): He is with me, and that's it!

Participants highlighted that their future was now due to their relatives' condition while hospitalised. Seeing their relatives in an unstable situation during hospitalisation increased their fear of losing the symbiotic relationship that existed between the informal carers and relatives due to death. Therefore, to safeguard the need for love and belonging, they avoided thinking about the future and lived day by day. Participants did not only confirm this notion of the future by words but sometimes even by facial expressions and silence when asked directly. However, when faced with this ambiguity of seeing no future, some informal carers tried to be resilient by appealing to higher entities by praying, especially when they were not with their relatives:

Whitney (wife and carer): (I was worried) that he is going to leave me [die]. I cried, 'Please, please, God, do not take him away from me. You cannot imagine how I was.

Participants tried to be resilient in stressful situations like admission and hospitalisation due to exacerbation of chronic diseases by praying. Evoking spirituality could indicate that the participants' self-efficacy was at stake, where they could no longer care for their relatives due to the patient's instability. However, during this period of separation the participants (informal carers) had two simultaneous perspectives, which were a close, detail-oriented perspective of the here and now (unstable relative) and a broader, more holistic and pessimistic perspective (praying to God and fear of dying). Informal carers during this period experienced an urge for a greater sense of belonging and love with their relatives which encouraged a sense of duty to be with their relatives more.

This crisis showed the vulnerability of the informal carers and awareness of their relatives' mortality that suddenly developed in a crisis during admission and hospitalisation. This relationship between vulnerability and awareness can be directly attributed to the patient's chronic illness and instability of their condition, thus admission and hospitalisation. Therefore, the informal carers shifted the focus from self to their relatives, especially when they were not near them. Informal carers were driven by the need to be near their relatives to continue their symbiotic relationship. Therefore, in the informal carers' minds, ignoring themselves and concentrating on their relatives during hospitalisation was doing what was right. This constituted an intense emotion of anxiety derived from the act of separation.

Wendy (wife and carer): When he was admitted there [resuscitation room], I thought he would die. I used to say, 'He is too young to die; he will not be able to spend time with his grandchildren.' I used to feel really sorry, but then I used to say I would leave it in God's hands, you know? Because after all, I might die before him, but I feel a lot for him. Because when there is love, you feel for him. If there is no love, you will not have feelings for him; that is what I think.

Another interpretation of the above could be that the separation experienced affected the positive thinking of the informal carers. During the separation, the informal carers could not stay positive, and feared that the patient might die and felt vulnerable. This impacted their thoughts by seeing an ambiguous future and turning to spirituality. Therefore, when the informal carers are faced with the instability of the patient during admission and hospitalisation and have to leave their relatives 'alone', they experienced *separation anxiety*.

Deborah (daughter and carer): After the cardiac ward, she was transferred to another ward. It's a really good ward, and I praise them for the work they do. But in a way, there is a drawback to being in a single room because if she was in a four-bedded or six-bedded area and something happened to her, one of the other patients would notice and call the nurses—that's what was my main worry: that she was alone, even though she was comfortable. Even though we were pleased because we could go and see her and stay near her more easily, but I used to worry that something could happen to her and no one would notice, especially when we were not near her.

This resulted in a higher state of vulnerability, constant worry about losing them, stress and anxiety, and thus striving towards resilience. Thus this evoked a sense

of vigilance in the participants over their relatives while hospitalised. As seen in the previous sections, they went out of their way to be near the relatives to constantly watch over them to avoid harm. However, another explanation could be the informal carers' past experiences (some participants experienced catastrophic events in the past and other participants were healthcare professionals) and/or the power relationship between the informal carers and the healthcare professionals (see Sections 5.5.1.3 and 5.5.1.4).

5.5.1.3 Disempowerment

The above two sections (difficulties in gaining access and separation anxiety) examined how admission and hospital affected the symbiotic relationship and provoked situations that influenced the informal carers' normal resilience, which resulted in informal carers being in a high vigilance state. In addition to this, the participants encountered other issues:

Quote 1

Dawn (daughter and carer): My brothers and sisters used to tell me, 'Do not make a fuss; do not stir up trouble because we depend on them [ward staff].' And it is true; we do depend on them.

Quote 2

Winter (wife and carer): You need to step back a little bit because you will be afraid that if you are perceived as arrogant, they [the healthcare professionals] might treat him [my husband] differently. Because when I am near my husband, it's one thing, but when I am not near him, I would not know what is happening. So you step back, hoping that they [healthcare professionals] take better care of him.

Although in the previous sections data showed very positive comments about the healthcare professionals involved, all the interviews carried out for this thesis noted the notion of being submissive to the healthcare professionals or hospital norms and the power differential between the informal carers and healthcare professionals. The participants (informal carers) expressed notions like 'we depend on them' or stepping back, which showed the power differential that existed in the hospital environment, and which left the informal carers no choice but to be submissive. This was adopted because the informal carers were concerned about the care of their relatives (patients) while they were not near them. The informal carers believed that the staff would treat their relatives well

by being unproblematic and a good informal carer. Therefore, to have their minds at rest, the informal carers had to abide by the hospital rules and norms and not complain or create problems. The hospital environment had its social norms and operational structure, which were established. Therefore, the informal carers recognised that the power shifted from their hands to the hands of the healthcare professionals. This was because it was more challenging to change the hospital norms. They needed to adapt by being submissive to have their minds at rest, so good care will be given to their relatives (patients). However, this peace of mind was not attained because the participants (informal carers) still had separation anxiety, as seen in Section 5.5.1.2. The informal carers still spent long hours near the relatives (patients) to watch over them to avoid harm and thus be vigilant.

Quote 1

Dominique (daughter and carer): You do get angry, and you would be tempted to damage them in the sense of reporting them.

Daphne (daughter and carer): We had actually filed a report,³⁸ but then we withdrew it because we thought that my father might need their help again in the future, and we were afraid of the consequences.

Quote 2

Darlene (daughter and carer): Nothing! You do not have any dignity; you are a number there, you have no dignity ... There's nothing we can do; we have to keep our mouths shut because she is the patient, and she will be alone during the night. During the day, at lunchtime or during the visiting hours, you are there as her advocate, but during the night, when we leave from 7 pm till 7 am, she will be alone... so you need to shut up and say nothing. And you talk to them [the ward staff] and tell them 'thank you very much' so at least the patient does not feel, or you do not feel that you left someone in danger. Not 'danger' as such, but you feel more secure that the night will pass and that we'll go again in the morning.

Although such submission was supposed to put the informal carers' minds at rest, the power differential between the informal carers and the healthcare workers had consequences for the informal carers. Being submissive affected the dignity

³⁸ The healthcare worker failed to consult the medical records, even when the informal carers informed the healthcare worker about the patient's past condition and admission, and a medical mistake was done.

of the informal carer because although they recognised that they were the advocates of their relatives (patients) while hospitalised, they failed to voice their concerns or report possible medical errors and dehumanising approach. This affected the self-efficacy, flexibility and positive thinking of the informal carers. This resulted in long hours of being near the patient or obsessively thinking about them vigilantly.

Darlene (daughter and carer): They [hospital staff] wanted her to wear a nappy, and she never wears a nappy. We never wear a nappy at home, and when she is home, she walks because she has a commode, and we arranged the house shower for her. But as soon as she is admitted to the hospital, they tell us that she is to wear a nappy. And of course, my mother feels scared.

Patricia (patient): No no and no.

Interviewer: How did you feel when they told you to wear the nappy?

Patricia (patient): I do not want to wear it.

Darlene(daughter): It is scary, you know, and we've been through this several times, but I don't want her to put on a nappy, and we always try to resist. So, we [her brothers and sisters] go there very early in the morning and take turns to be near her all, but not during the night because everyone has to rest a bit. But we leave her alone the least time possible, and then we will go again as early as possible in the morning, so, if possible, we help her go to the toilet and avoid the nappy. She can take lactulose and supps to help her; these are basic things. She is 84, and she never had a nappy, and we absolutely do not want her to wear a nappy.

As highlighted in the above quote, the hospital staff's imposing of a hospital routine showed how the participants (both informal carers and patients) felt embarrassed, dehumanised, and stressed. One possible explanation could be that the hospital staff could be so entrenched in a routine of care that they forget the personal nature of their job. The unique nature of the hospital staff's job could be to identify the deep relationship that exists between the informal carers and their relatives (patients). One important phrase that was noticed from the above quotes was 'we never wear a nappy'; here, the participant identified herself with her mother. This showed the depth of their relationship. The identification and recognition of this relationship by the hospital staff could be necessary for the informal carers to cope in a stressful environment. Furthermore, to compensate

for the imposing routine of the hospital staff, the informal carers went early in the morning before their work. They spilt and organised the days between themselves and friends to avoid leaving their relatives (patients) alone.

This notion of imposing the routine was evident and corroborated by five other participants. In contrast, one participant (Danielle) accepted this imposing of a routine and abided by the hospital routine and rules more willingly. One must note that Danielle was a healthcare professional and could 'bend' the rules and routine in her favour. However, this did not happen, and Danielle was submissive to respect her colleagues and the hospital routine. This resulted in a higher level of anxiety and obsessively thinking about her father because Danielle could not be near her father, as described in Section 5.5.1.2. Therefore, the above indicated how the informal carers interacted with and reacted to the hospital culture, norms and staff. The informal carers sometimes challenged the hospital social norms (imposing the routine), but they had to be submissive because they wanted their mind at rest that someone was taking care of their relatives when they were not there. On the other hand, one can differentiate between the cultural norms of the hospital environment, regulations and praxis and from the social norms of the participants' relationship (between patient and informal carers) based on years of knowing each other, acceptance, support, companionship and trust. When an admission occurred, the relationship between the informal carers and the relatives was disrupted, and the informal carers were expected to abide by the hospital social norms (such as visiting hours or imposing a nappy). This resulted in a conflict within the informal carers by going against the hospital norms (pushing for not having a nappy or ignoring hospital visiting hours) or abiding by the hospital social norms (being submissive). One can argue that this conflict could have arisen because the informal carers were not used to the hospital social norms. But this was not the case because most of the participants had spent a lot of time in hospital during the past years due to frequent admissions. Even those participants (informal carers) who were part of the hospital social norms (such as being healthcare professionals) expressed the same concerns. Furthermore, the informal carer could have transferred or imported norms from home to the hospital environment. This was done because the informal carers had no clear and written indications (apart from visiting hours) of how they could act while in hospital. To determine the best course forward, the informal carer

typically relied on what they had done in the past and at home (not putting on the nappy and taking care of their relatives).

Whitney (wife and carer): Whenever you tell them [hospital staff] something, it's like they tell you 'We know more than you do,' you know?

Interviewer: right...

Whitney (wife and carer): And you shut up.

Interviewer: But do you really think that they know better or not? Tell me.

Whitney (wife and carer): No. Let me tell you: I have known my husband for almost 60 years; therefore, I know him better than they do, you know? But there are times when... even for the pills, I used to make sure that he takes them at a certain time. There [hospital], they give him pills whenever they feel like it, so to speak [she smiles] ... So I think that I know him better than they do...

However, the shift in care control from the informal carers to the hospital staff while hospitalised was more evident when the informal carers were not being recognised as informal carers. Participants (informal carers) argued that they knew their relatives (patients) much better than the hospital staff due to their symbiotic relationship. However, the participants (informal carers) felt that the hospital staff did not recognise them as the informal carers of their relatives, which made them feel that their knowledge was of no consequence as the hospital staff knew better than them.

Deborah (daughter and carer): You feel it a lot [not being recognised as a carer]. As soon as she was admitted, it's like she became theirs in a way; the patient is no longer yours. In fact, you, as a carer, wouldn't be able to give your input in certain situations. For example, I know that my mother has a lot of ulcers because of her diabetes and poor circulation, and I used to change her dressing twice a week while she was at home. Then when she was hospitalised, I skipped Friday's change of dressing as I was unable to visit, but by then, it was Tuesday, and I started to worry because the dressing had not been changed for one week. And I thought I'd better just do it myself. I had everything with me. I had everything I needed for the change of dressing, so I didn't need to ask them for anything. So, I just did it there and then. However, the following morning they phoned me to ask why I had interfered and to say that I wasn't supposed to do the change of dressing because the patient was now theirs and not mine since my mother was not at home.

Interviewer: How did you feel?

Deborah (daughter and carer): I felt bad... really bad. I really felt that I am not trusted. I was worried that they [hospital staff] were saying that I was interfering. I was worried that they thought I liked to interfere and overstep or didn't trust them. I felt awful. I tried hiding this from my mum, but she was anxious too and told me, 'I should never have told them that you changed the dressing.' Indeed, I didn't tell them about it, but that's because it was part of my routine and not because I wanted to hide anything from them. In fact, I didn't even close the curtains or anything like that because I had nothing to hide. I just told her [mother], 'Come on, let's change the dressing.' But yes, looking back, it was a really uncomfortable feeling... after so many years as her primary caregiver; all of a sudden, all the care is taken away from your hands.

This clearly impacted the self-efficacy of the informal carers and affected their self-esteem and confidence in taking care of their relatives. Not being recognised as an informal carer was evident in another four interviews. Two participants (Dominique and Daphne) described how the healthcare professionals sometimes ignored them and did not want to hear their 'story' when their father was admitted.³⁹ Another participant (Dawn) described how she was not even allowed to accompany her mother to the toilet. The participants felt this was degrading and emphasised to the hospital staff that they took care of their relatives every day while at home. Therefore, this showed that there was a shift of power and control when the patient was admitted. The informal carers' self-efficacy in taking care of their relatives while hospitalised was somewhat diminished. The healthcare professionals did not sometimes approve or recognise the informal carers' normal behaviour of being the carers of their relatives.

The above data explained how participants were affected by the hospital environment, staff and culture (the hospital social norms). The hospital social norms were derived from a collective presentation of the acceptable ground conduct⁴⁰ (during hospitalisation), as well as individual perceptions (by both informal carers and patients) of particular group conduct (healthcare professionals). While at home, the social norms were that the informal carers took care of everything for the patient, which was as expected (as seen in Section

³⁹ Which led to a medical error.

⁴⁰ To abide to the visiting hours, to leave the care to the healthcare professionals.

5.2), whereas, while the patient was hospitalised, the social norm was that patient care was no longer the domain of the informal carer. Still, care was shifted to the healthcare professionals, and the informal carers were expected to obey their norms and submit. The social norms between the informal carers and their respective relatives had developed informally due to long-standing symbiotic relationships. There were no written laws per se, but informal care norms represent generally accepted and widely sanctioned routines that informal carers and their relatives follow in everyday life, as seen in Section 5.3. Hospital admission disrupted the social norms between the informal carers and their respective relatives, thus affecting their symbiotic relationship and resilience. Participants (informal carers and patients) highlighted various issues which prevented the participants (informal carers) from taking care of their relatives, as well as the power shift of care from the informal carers to the healthcare professionals.

Admission and hospitalisation affected the symbiotic relationship between the informal carer and the patient (as seen in the above sections). Therefore, the participants experienced power issues due to changes in the informal care environment (from home to hospital) and a shift of care from the informal carers to the hospital staff. This resulted in issues where the informal carers tried to cope with these power issues or disempowerment. However, *disempowerment* in this thesis meant that the informal carers had to submit to the hospital culture, norms and power by being compliant informal carers. The informal carers lost the feeling that they could influence the care of their relatives and the direction of how the recovery of their relatives would have occurred, thus resulting in a break in normal resilience. This disempowerment of the informal carers during the hospital stay could have had a devastating effect on the self-efficacy of the informal carer, affecting their positive thinking and flexibility, as seen in the quote below:

Darlene (daughter): It is scary, you know, and we've been through this several times, but I don't want her to put on a nappy, and we always try to resist. So, we [her brothers and sisters] go there very early in the morning and take turns to be near her all, but not during the night because everyone has to rest a bit. But we leave her alone the least time possible, and then we will go again as early as possible in the morning, so, if possible, we help her go to the toilet and avoid the nappy. She can take lactulose and supps to help her; these are basic things. She is 84, and she

never had a nappy, and absolutely we do not want her to wear a nappy.

Furthermore, from the data presented in this section, it was noted that admission and hospitalisation, which provoked the disempowerment and thus a break in normal resilience, resulted in a loss of dignity, lack of control, the invisibility of the informal carers, the vulnerability of the informal carers, but even the caring side of the informal carers. Thus, this evoked an emotional reaction to the informal carers' vigilance, as seen in the above quote and other quotes presented. These aspects will be further elaborated on and discussed in Section 5.6.

5.5.1.4 Duality

In the above sections, the participants described the continuous struggle to be near their relatives (difficulties in gaining access), the disempowerment and separation anxiety caused by admission and hospitalisation, and thus a break in the symbiotic relationship and a break in normal resilience. In the interviews, the participants described other consequences of a break in the symbiotic relationship:

Deborah (daughter and carer): But the thing is not about her being in hospital as such. The problem was mainly that my mother and father were apart, and we used to worry for both of them. We used to feel like being split in two. When she was in the hospital, my sister and I said, 'So I will go to the hospital from 6 to 8, and you come here [their mother and father's house], you know. [first interview]

Participants identified various forms of duality which impacted their response while their relatives were admitted and hospitalised. The participants described juggling between being near their hospitalised relatives and worrying about other relatives (not hospitalised) as 'being split in two'. This was conceptualised as a duality, which in this context means being metaphorically split in two to maintain balance in different roles that informal carers had while their relatives were hospitalised. Deborah explained what it was like to be in a two-state of being – being near her mother and being near her father in two different places (hospital and home). Despite knowing that she could not physically be in two places simultaneously to take care of both her mother and father, she was still in a state of worry and anxiety. To cope with this situation, participants draw on their social support to try to cope with the situation (admission and hospitalisation).

As seen in Section 5.5.1.2, one can argue that the duality component in the informal carers' life was always present, even when their relatives were at home. However, the difficulties in gaining access, disempowerment, separation anxiety, and unmet relationship needs exacerbated this notion of duality. As seen in the Section 5.5.1.1, the personal commitments of the informal carers prevented them from being near their relatives when hospitalised. Therefore, from the data presented in Section 5.5.1.1, this could be interpreted as role duality: the participants need to be present near their hospitalised relatives but at the same time need to take care of other family members or go to work. Participants described how admission went against the relatives' wishes in the status quo bias. Still, they knew that the best choice was admission, which could be described as responsibility duality. Consequently, role duality and responsibility duality resulted in blaming themselves and affected their self-efficacy, thus, affecting their positive thinking by feeling that they were not taking care of their relatives, not doing their job as informal carers and therefore letting their relatives down. More examples of duality were seen during the interviews:

Quote 1

Whitney (wife and carer): ...and I heard him (the consultant) shouting and telling the nurse in the corridor, 'Go near him; he is the most unstable patient we have in the ward'. And I told my son: 'He is referring to your father.' He said it wasn't the case, but I immediately understood that he was talking about him [her husband] because he really was. Do you know enough what I mean?

Interviewer: When you heard him saying that he is the most unstable patient they have, how did you feel?

Whitney (wife and carer): I wanted to die, felt really bad, and didn't want to let him know...

Interviewer: Why did you act like this?

Whitney (wife and carer): You have to! If he sees me sad or crying, it will make him feel worse. I used to make sure I wouldn't cry in front of him.

Interviewer: To give him courage?

Whitney (wife and carer): Because I needed to give him courage. You know how it is when a person sees a sad and nervous face. It was no joke.

Quote 2

Danielle (Daughter and carer): Yes, I tried to cope with the help of others. In my case, I wouldn't eat, I wasn't in the mood to go out (socialising), I was constantly crying, constantly thinking. I still try to go to work and get on with my life as much as possible. However, during my father's last admission, psychologically, I was not in a state to go to work. Yes, I didn't go to work because it was unsafe for my patients and me. Other than that, had I been alone without any help, my life would stop there and then. However, with the help of my immediate family and my partner, I was able to get on with my life and be near my father.

Participants described how they tried to be strong for their relatives, but at the same time, they were really anxious and shocked. This could be conceptualised as an emotional duality. The informal carers had to suppress their feelings in front of their relatives to give their relatives courage, especially during hospitalisation. This emotional duality was evident in four other interviews. The expectations of being an informal carer were that they should be the main giver of care and help their relatives (patients). Furthermore, the informal carers were expected to be strong in front of their relatives and ignore their own basic needs, especially during hospitalisation. On the other hand, the struggle to be strong did not mean that the informal carers did not need help. All the informal carers interviewed sought help and support for themselves. Therefore, a caring duality (the caregiver and the care receiver) was seen very often during all the interviews.

Deborah (daughter and carer): I used to feel really, really guilty. At the same time, I felt tired, and I saw work as an unnecessary burden. I felt I couldn't give my all at work, but at the same time, I felt guilty. However, staying near my mother to see what was going on was the only thing that used to calm me. I felt a lot worse away from my mother because I didn't know what was happening, and I was constantly apologising to my staff because I was feeling really bad. For example, certain things at work would break down, and I was like, 'My goodness; I didn't even report them because it was time to pick up my children and go near my mother.'

The consequence of duality was an increase in the informal carers' sense of lack of control over their care of their relatives and personal life. However, at the same time, the participants wanted to be near their relatives (patients) to watch over them and thus be vigilant. Furthermore, their presence near their relatives calmed

them down, but they still had to work or take care of other family members. This continuing struggle and guilt feeling was exacerbated when their relatives (patients) were admitted, and a break in their relationship was noted.

Peter (patient): It would be good if all the children were like them [their children].

Interviewer: What would it be like if you didn't have the help of your children?

Winnie (wife and carer): Oh, only God knows how I would have ended up. We will have to go to a home for the elderly if they accept us. We would have to do what others do. What can you do if you have no one to help you? But until now, with the help of God, they have always helped us.

Consequently, the informal carers draw on their social support and spirituality to cope with this situation by being more vigilant of their relatives. However, the informal carers were clearly not coping with the situation as most of the participants did not adapt to the challenges of the admission and hospitalisation, as seen in the above quotes. Positive thinking was affected because they had guilt feelings and fear of death at that moment. Although, most of the time, when the informal carers were resourceful at home, an admission and hospitalisation of their relatives (patients), thus duality, affected their needs and feeling of accomplishment (in this case, being near the patient and thus being vigilant). However, past experiences were another aspect mentioned during the interviews that could have affected the informal carers' duality and coping ability.

5.5.1.5 Past experiences

Past experiences were based on a long relationship that the informal carer had with the patient, whether that was a wife, husband or daughter, which has already been described as symbiotic in nature in the above sections. Therefore, the symbiotic relationship was based on their past experiences of being informal carers, which all participants highly valued. The experience was a common and recurrent theme that affected all the participants in this study. The informal carers compared their past experiences with the present, made continuous reference to their past, compared it to the current situation and reconstructed how they felt after those events. This affected the response and actions of the informal carers during the admission and hospitalisation of their relatives. The three participants who were healthcare professionals saw a lot of patients dying during the night,

and therefore felt anxious when their relatives were 'alone' during the night. They increased their watchful state by continuously phoning their relatives (patients) and the ward staff to check on them. Furthermore, being healthcare professionals, taking care of other patients with the same condition made them constantly alert and watchful when their relatives were admitted. This was because they knew the consequences of hospitalisation on elderly patients (infections, bedsores, and death). Other participants had had near-death experiences with their relatives in the past. To compensate for this state of anxiety, they increased their watchful state and spent a lot of time with their relatives and obsessively thought about them. Furthermore, a participant lost her husband during the night,⁴¹ which affected how she acted when her mother was hospitalised (she literally detached herself socially and was always with her mother or thinking about her). In the above reactions, the informal carers seemed to excessively dwell on their past experiences, making them more anxious, and thus not living in the present. However, recurrent admissions and experiences helped some participants in 'saving' their relatives by staying near them:

Daphne (daughter and carer): It's like I started to feel something, but I do not know how to explain it.

Interviewer: Where do you think this is coming from?

Daphne (daughter and carer): You know what? I think it is because my father has a long history of illness and we are near him all the time. For example, I quit my job to take care of my father because he was admitted so many times. I think it's because I am getting used to a lot of things.

Interviewer: So, did your experience help you a lot?

Daphne (daughter and carer): My experience helped me a lot. I think I am getting better and more knowledgeable than a doctor [laughing].

Here the participant stated how she 'felt something' in her which told her to be more watchful and stay near her father. The participant attributed this feeling to years of experiences and multiple readmissions of their father. The informal carer had an intuitive grasp of the situation, which helped her understand her father's condition without excessive thinking or reasoning. This notion of intuition was

⁴¹ Massive haemorrhagic cerebrovascular accident which led to his death.

further corroborated by other participants in the study (Darlene, Whitney, Deborah, Winnie, Dawn, Danielle, Winter, Dominique). However, all the participants still felt guilty and were anxious whatever they did; this could be attributed to the fear of death and separation anxiety they experienced during their life. The participants constructed how their *intuitive knowledge* influenced their mood and feelings and how they acted. All participants recognised that their *intuitive knowledge* increased or decreased their watchful state accordingly. Therefore, *intuitive knowledge* for this study consists of years of experience being an informal carer, the participants' past personal experiences of taking care of other relatives, and the participants' medical knowledge acquired during years of taking care of their relatives. In other words, this *intuitive knowledge* helped to a certain extent the informal carers in adjusting to specific situations (staying near their relatives to avoid harm). However, this continuous evoking of past experiences and knowledge could have prevented them from coping during hospitalisation, thus evoking a range of emotions (anxiety, fear and more). Consequently, the informal carers were not acutely coping but struggled to take care of their relatives in the hospital setting, thus being vigilant.

5.5.2 Striving towards resilience

The above sections noted that the informal carers had *a break in normal resilience* and therefore were *striving towards resilience*. Striving towards means that the informal carers were vigorously trying to bounce back, cope, adjust or adapt to admission due to the sudden onset of CHF symptoms. While in Section 5.5.1 normal resilience was presented, the above sections showed that informal carers were not achieving resilience because various factors were affecting their normal resilience. Thus a break in normal resilience occurred. Although the informal carers sometimes accepted help from the nurses and other family members/friends, they still spent a lot of hours near the patient and still engaged in overthinking about their relatives. Therefore, although they were trying to be resilient by accepting help from others (social support), they were still not being resilient. Another factor showed that the informal carers were striving or trying hard to cope when they tried to be flexible. Although the informal carers tried to let go of the patient in the hands of the hospital staff or other relatives and/or obey hospital rules and norms, they still challenged these norms and regulations, still passed a lot of time near the patient, still bargained their way in, still overthought.

Some stated that their life literally stopped. This could be explained by the informal carers having habits and beliefs different from the hospital norms and the hospital staff, making it difficult to adapt or be resilient. Furthermore, the informal carers draw a lot from their past experiences and try to adjust or sometimes contest the hospital social norm. However, this placed the informal carers in a difficult situation of challenging or not challenging the hospital social norm for the patient's benefit (the ability to be flexible). Furthermore, the informal carers felt the discomfort of not being near the patient or seeing the patient in an unstable situation and sometimes strongly expressed themselves (e.g., banging their head against the wall).

On the other hand, the informal carers embraced their past and brought their experience to the present; however, they did not manage to see a future due to the nature of the chronic illnesses and the instability of their relatives' condition. During the hospitalisation, the informal carers did not have time to stop and think about what was happening. The informal carers tried to accept this sudden admission and embrace it; however, due to the hospital social norms, power issues, unstable patient conditions, and personal issues they didn't have time to be resilient. Due to the above, the informal carers struggled to take care of themselves and make every day meaningful for them but looked forward to achieving back the status quo. Furthermore, resilience was based on a caring and supportive relationship within and outside the family, creating love and trust and offering encouragement and reassurance. This type of relationship was conceptualised as a symbiotic relationship by the participants. Sudden admission and hospitalisation prevented this relationship between the informal carer and the patient because of less time, separation, and power issues. Thus, for this reason, the informal carers were struggling but at the same time striving towards resilience.

Quote 1

Deborah (daughter and carer): My sister and I were really stressed during that period.

Quote 2

Darlene (daughter and carer): Whenever she is in an acute phase, I am really anxious because I think that she [her mother] is going to die... because you feel really hopeless and you have

to thank them [hospital staff] even though you feel hopeless..... here at home I everything under control, while there [at the hospital] you lose everything because there [hospital] you have nothing, there you are in their hands [hospital staff] that's it

Quote 3

Winter (wife and carer): When they [hospital staff] tell you that he [her husband] has something wrong in his heart, I was shocked because I never expected it. When was he admitted? I used to be near him all the time because he would constantly be on your mind, and you would constantly be thinking, 'What is happening? What is going to happen?' You wouldn't know what might happen and you wait...

The consequences of this striving towards resilience resulted in the participants constantly thinking about their relatives and waiting to be near them (watchful waiting). Moreover, it resulted in the participants losing control and thus increasing their presence near the patient to avoid harm to them. Thus, they increased the state of vigilance on their relatives.

5.6 Identifying the core category – Vigilance

In the above sections, the meaning of the social process was given for the process of admission and hospitalisation that affected the informal carers' care of their relatives suffering from CHF. Furthermore, a conceptualisation and the meaning of the informal carers' and the patients' relationship was given. From the data above, six main categories were co-constructed: the symbiotic relationship, a break in the symbiotic relationship, a break-in-life trajectory, striving towards status quo, a break in normal resilience, and striving towards resilience. Consequently, the above categories were characterised and linked together by codes of *intuitive knowledge, loss of control, unmet needs, emergency, sudden onset, emotional turmoil, status quo bias, separation anxiety, disempowerment, gaining access (difficulties), duality, hospitalisation, admission, exacerbation instability, status quo, Maslow's needs met, resilience, long-term bases, one being, intimate interaction, relying on each other, acceptance, support, companionship and trust*⁴².

⁴² The word in italics presents the connecting concepts between the main categories see figure 6 in section 6.2

From the above categories and quotes (see quotes in Section 5.3.1, 5.3.3, 5.4.2, 5.4.3, 5.5.1.1, 5.5.1.3, 5.5.1.4) presented in this chapter, it was noted that the reactions of the informal carers during admission and hospitalisation could be explained as **Hospital High Vigilance**⁴³. Hospital High Vigilance in the context of this study is represented in the informal carer's act of keeping watch for possible danger or difficulties that could happen during admission and hospitalisation of their relatives. All the participants in this study mentioned a form of vigilance in one way or another. Hospital High Vigilance was seen as a central category because it explains the informal carers' reactions when admission and hospitalisation happened. This emergency admission and hospitalisation affected the relationship between the participants (informal carers and patients). Because of this, Hospital High Vigilance explains why informal carers went to extremes to be near their relatives to watch over them. This type of vigilance is different from vigilance at home for various reasons, the main reason being a break in the symbiotic relationship, which exacerbated the fear of losing this relationship. However, as seen in the above sections, the Hospital High Vigilance core category was characterised by *vulnerability, presence, constant watchfulness, lack of control, harm avoidance, watchful waiting, advocacy, duty, invisibility, caring, and loss of dignity*.

Most of the time, the instability and vulnerability of the patient take over in an emergency situation. However, the data above indicated the vulnerability of the informal carers during admission and hospitalisation. *Vulnerability* refers to the inability of informal carers to cope or be resilient in order to withstand the effects of admission and hospitalisation and the possibility of losing their relatives. During the interviews, this was shown in various instances, mainly by emotional turmoil (fear, grief, guilt feelings, and many more) and seeing no future (see Sections 5.3.1, 5.3.3, 5.4.2, 5.4.3, 5.4.4, 5.5, 5.5.1.1 and 5.5.1.2). However, the informal carers were always present near their relatives while hospitalised. *Presence* represents the informal carers always willing to be present near their relatives even when they are not allowed or cannot (see Sections 5.3.1, 5.4.2, 5.4.3, 5.5.1.1, and 5.5.1.2). Although the informal carers were most of the time near the patient, they expressed their frustration when they were not considered or

⁴³ Bold represent the central organising concept see figure 6 in section 6.2

recognised as their informal carers by the hospital staff. This was conceptualised as *invisibility* and meant that although the informal carers took care of their relatives at home when their relatives were admitted, the care was shifted to the hospital staff and sometimes the hospital staff did not consult or ask or recognise them as informal carers (see Sections 5.5.1.1, 5.5.1.3 and 5.5.1.4). This highlighted the *lack of control* that the informal carers experience in the care of their relatives during hospitalisation, but some informal carers had even lost control of their personal life due to over-anxiety over the situation (see Sections 5.3.1, 5.3.2, 5.3.3, 5.3.4, 5.5, 5.5.1.1 and 5.5.1.2). Furthermore, this lack of control and invisibility highlighted the *loss of dignity* that the informal carers experienced during this period. The loss of dignity was not seen only in the informal carers because they were not recognised, but even in the patient when a routine was imposed on them, like putting on a nappy (see Sections 5.5.1.1 and 5.5.1.3). Most of the participants (informal carers) identify themselves with their relatives (patients). Therefore, if they feel that the patient has lost their dignity, they feel that they have lost their dignity. However, the informal carers still considered themselves the patient's *advocate* to avoid harm when they went against the hospital routines (putting the nappy) or when there was an indication of medical error (see Sections 5.5.1.3 and 5.5.1.4). This highlighted the sense of *duty* that the informal carer has on their relatives' care: they do not see it as a burden (see Sections 5.3.1, 5.3.3, 5.4.1, 5.4.3, 5.4.4, 5.5.1.1, 5.5.1.2, and 5.5.1.3). Therefore, this theory highlights the *caring* side of the informal carers while their relatives were hospitalised by being constantly watchful (*constant watchfulness*) (see Sections 5.3.3, 5.3.4, 5.5.1.1 and 5.5.1.2). Constant watchfulness represents the act of always watching their relatives to avoid harm (*harm avoidance*) (see Sections 5.5 and 5.5.1.5). However, sometimes informal carers had to leave their relatives alone when asked by the hospital staff and because they had other personal commitments which they could not refuse. Still, they watched what was happening to their relatives by phoning the ward, not switching the phone off, not engaging in social activities, and leaving someone else near their relatives while they were away. This is because the informal carers were eagerly waiting to be near their relatives, but at the same time, they watched over them even if they were not physically near them (*watchful waiting*) (see Sections 5.3.3, 5.5.1.1, 5.5.1.2 and 5.5.1.3).

Therefore, being vigilant is a way for the informal carers of trying to cope or hold on to their symbiotic relationship in an admission and hospitalisation situation. Therefore, the Hospital High Vigilance theory is a comprehensive explanation which has centrality, frequency, relevance, grab and variability for how the informal carer's self of a patient with CHF was co-constructed by the respective informal carers during admission and hospitalisation.

Chapter 6: Discussion

6.1 Introduction

The previous chapter presented the findings from interviewing the participants (informal carers and patients) about their perspectives and experiences of informal care of a patient suffering from CHF during admission and hospitalisation. Emerging from the data was a possible explanation of how informal carers take care of a patient diagnosed with CHF, and the researcher constructed the concept of Hospital High Vigilance. This was done by examining the social processes involved in informal care during admission and hospitalisation. This chapter will now focus on and synthesise the data and develop this explanation into a new substantive theory that will illuminate the social process of informal care of patients suffering from CHF during admission and hospitalisation. Hospital High Vigilance had emerged as the core and central concept explaining informal care during admission and hospitalisation. The Hospital High Vigilance theory integrates concepts that lead to the informal carers' high vigilance during admission and hospitalisation. The concepts were condensed into symbiotic relationship, a break in a symbiotic relationship, a break-in-life trajectory, striving towards status quo, a break in normal resilience and striving towards resilience (see Figure 6). This chapter will rationalise how the Hospital High Vigilance theory constructed from this research study contributed to new knowledge.

6.2 The theory of Hospital High Vigilance

The Hospital High Vigilance theory is represented in Figure 6, which shows the social process of informal care during admission and hospitalisation of patients suffering from CHF.

The substantive theory starts with explaining and giving meaning to the relationship between the informal carer and the patient suffering from CHF. The relationship was conceptualised as a symbiotic, long-term relationship based on years of knowing each other and identifying themselves as one being. During these years of being together, participants developed an intimate interaction. They rely on each other, accept the chronic illness of their relatives, support each other through companionship and trust. The everyday lifestyle and routine (the informal carers' respective homes) was conceptualised as status quo. Status quo

in this context means that the informal carers preferred the stability and the untouched nature of their home situation, where they were in charge and could cope or be resilient in their routine and lifestyle. The informal carers could manage or bounce back in an adverse situation and preferred to remain in their home environment or everyday routine to meet their needs as a couple. This could be identified as a normal relationship between a husband and wife, a mother and a daughter, a father and a daughter. However, this relationship somewhat changed or was affected when the patient suffered an exacerbation of CHF symptoms. The instability of the patient suffering from CHF required admission and hospitalisation. This changed the relationship, which was conceptualised as a break in the symbiotic relationship between the informal carers and their relatives. This break in the symbiotic relationship resulted in the unmet needs of the informal carers and loss of control to the care that informal carers took of their relatives while at home, and thus an increased vigilant state of the informal carers.

Also, admission and hospitalisation affected the relationship between the informal carer and the patient by less contact time due mainly to hospital policies or norms and personal commitment. Consequently, the break in the symbiotic relationship, the status quo bias (trying to maintain normality), an emergency situation provided by a sudden onset of the CHF symptoms, and the patient's unstable condition evoked a range of emotions or emotional turmoil. Thus, a break-in-life trajectory was conceptualised from the data, which meant a disruption of the normality or lifestyle of the informal carers and their relatives. They could not do what they usually did every day with their relatives (patients) while hospitalised. The process of a break-in-life trajectory resulted in the informal carers striving towards the status quo (trying to go back to the normal routine) during admission and hospitalisation of their relative. The break in the symbiotic relationship led to a break-in-life trajectory, which led to striving towards the status quo, evoking a high sense of vigilance from the informal carers.

Also, a break in the symbiotic relationship evoked separation anxiety, disempowerment, difficulties in gaining access to the patient, duality and unmet needs. Separation anxiety in this context means that when the informal carers were not near their relatives, it impacted their relationship's love and belonging needs. Difficulties in gaining access mean the difficulties the informal carers

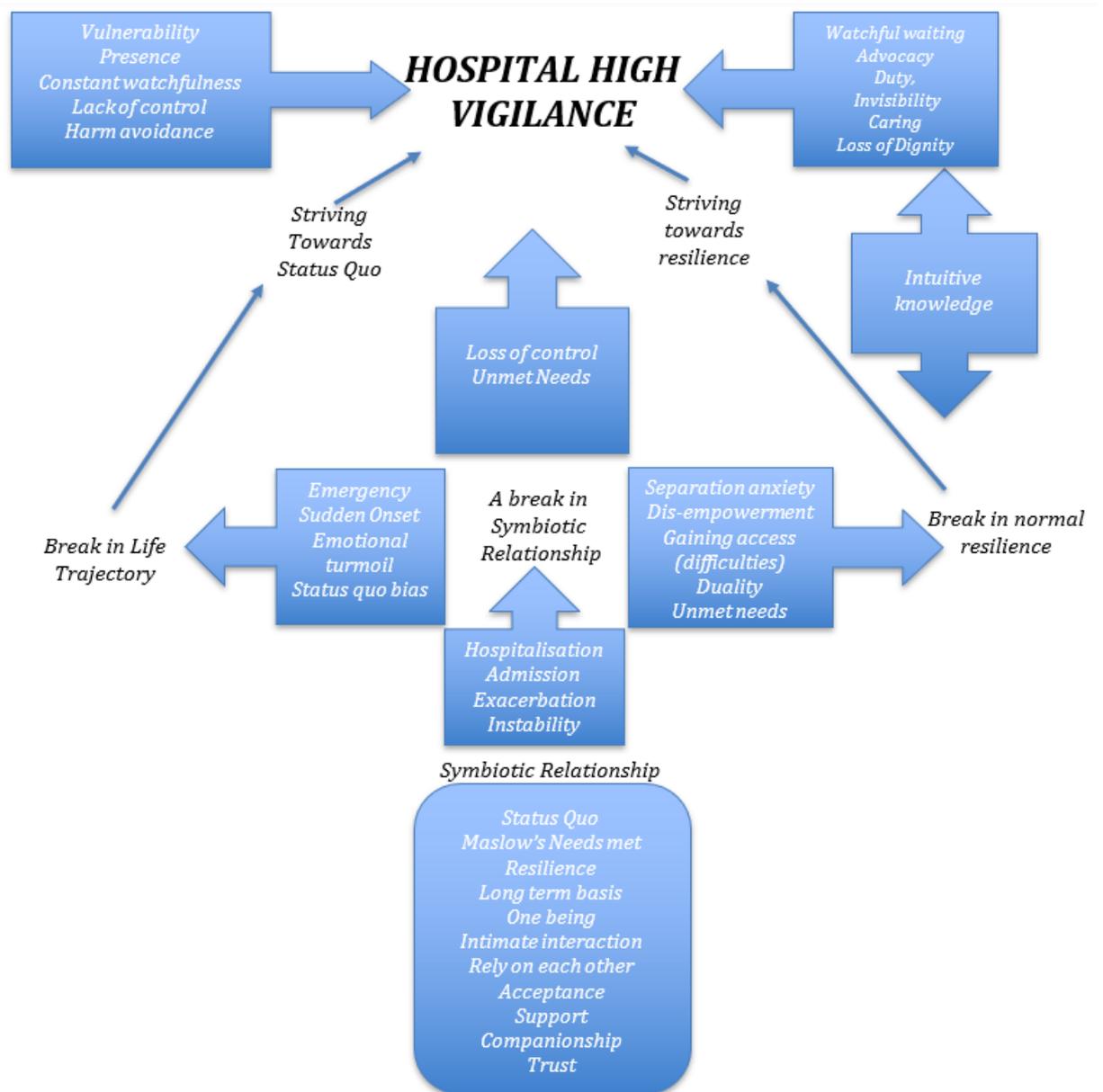
encountered to be near their relatives while their relatives were hospitalised to be able to care for them or watch over them. Disempowerment in this theory means that the informal carers had to subdue the hospital culture, norms, and power by being compliant. Duality in this study context means being metaphorically split in two to maintain balance in informal carers' different roles while their relatives were admitted and hospitalised. Thus, separation anxiety, disempowerment, difficulties in gaining access, duality and unmet needs provoked a break in the informal carers' normal resilience. A break in normal resilience means that the admission and hospitalisation of the patient affected the normal way of coping or bouncing back from the informal carers. Thus, the informal carers were striving towards resilience; they were trying to bounce back or cope with the admission and hospitalisation of their relatives (patients). Consequently, the break in the symbiotic relationship that led to a break in normal resilience led to striving towards resilience influenced by the past experience of informal carers (conceptualised as intuitive knowledge) provoked a high sense of vigilance from the informal carers.

The above concepts lead to the central organising theme of Hospital High Vigilance. Hospital High Vigilance is defined as the informal carer's act to keep providing care in case of possible danger or difficulties that could happen during admission and hospitalisation of their relatives. Informal carers perceived that the only way they could still care during admission and hospitalisation of their relatives was to be vigilant. This is shown in the core category of Hospital High Vigilance's characteristics of vulnerability, presence, constant watchfulness, lack of control, harm avoidance, watchful waiting, advocacy, duty, invisibility care, and loss of dignity. Vulnerability derives from the informal carers' inability to cope due to the possibility of losing their relatives (patients) during admission and hospitalisation. This pushed the informal carers to increase their presence near their relatives (patients). Although the informal carers increased their presence near the patients, they expressed frustration when the hospital staff sometimes did not consider or recognise them as informal carers. Thus, invisibility arises due to not being consulted or asked or recognised as informal carers of their relatives even if they took complete control and care of their relatives at home. The lack of control of the informal carers over the care of their relatives during admission and hospitalisation was even evident in their personal life when they lost control of

their routine (work and personal commitment disruptions) and control on the care of their relatives (patient). This evoked a sense of loss of dignity because they were not recognised as informal carers and they the hospital routines imposed on them. The informal carers highlighted a sense of advocacy to avoid harm to their relatives (patients), which highlighted a sense of duty to care for their relatives, which they did not perceive as a burden. Thus, this showed the caring side of the informal carers by being constantly watchful during their relatives' admission and hospitalisation to avoid harm. However, when the informal carers had to leave their relatives in hospital, they were waiting to be near them again and watched their relatives by phoning the ward, not switching off the phone, not engaging in social activities, and leaving someone else near their relative while they were away.

In summary as seen in Figure 6 below, Hospital High Vigilance theory is characterised by six categories (symbiotic relationship, a break in symbiotic relationship, a break in life trajectory, break in normal resilience, striving towards status quo and striving towards resilience) and one core category (hospital high vigilance). The first category of this theory is the symbiotic relationship, this category is characterised by various codes which describe the relationship between the informal carers and the patients (see fig 6). The symbiotic relationship is connected to the category of a break in symbiotic relationship by codes of hospitalisation, admission, exacerbation, and instability. From a break in symbiotic relationship, three different pathways can be noted. The first pathway is connected to the core category of hospital high vigilance by the codes of loss of control and unmet needs. The second pathway is connected to the category of a break in life trajectory with codes emergency, sudden onset emotional turmoil, and status quo bias which in turn leads to the category striving towards status quo and the core category hospital high vigilance. The third pathway is connected to a break in normal resilience by codes separation anxiety, dis-empowerment, difficulty in gaining access, duality, and unmet needs which in turn leads to the category striving towards resilience and to the core category hospital high vigilance. The break in normal resilience is also connected to hospital high vigilance by the code intuitive knowledge. The core category of hospital high vigilance is characterised by various codes as seen in fig 6.

Figure 6: Social process leading to Hospital High Vigilance Theory



6.3 Situating the theory within the broader literature

The Hospital High Vigilance theory will now be contrasted with existing literature to reveal how this new theory challenges, contributes to and extends current knowledge. This discussion is built on a literature search based on the data emerging from the interviews conducted to construct the theory. In view of this, the literature search can be defined as a traditional narrative literature review because there was no review protocol, and no particular search strategy was adopted (see Appendix 23 for an example of the search). Still, the search was conducted using the emerging concepts from the data. I recognise that the search and discussions, although guided as much as possible by the emerging concepts,

were influenced by the researcher to some extent. Therefore, this discussion cannot be reproduced independently as conclusions may be subjective. This aligns with constructivist grounded theory's philosophical and methodological stances, as explained in Chapters 3 and 4.

6.3.1 Hospital High Vigilance theory and vigilance in literature

To understand and explain the term vigilance, it is helpful to examine established publications about the concept of vigilance, which was the central organising phenomenon within the Hospital High Vigilance theory about informal care of a patient suffering from chronic heart failure during admission and hospitalisation. During the literature search about vigilance, literature was found in other areas of care that addressed vigilance as a concept, theme or label which will be discussed and analysed according to the Hospital High Vigilance theory. From the literature search, one theory about vigilance was found (Family Vigilance, by J.M. Carr), which was mentioned in four studies (Carr and Clarke 1997, Carr and Fogarty 1999, Dudley and Carr 2014); another two studies (Mahoney 2003, Lee and Lau 2012) were found which mentioned the concept of vigilance as a central aspect of their studies. Most of the other literature identified vigilance as a sub-theme of a theory or one of the themes discovered, and this will be discussed and compared to the Hospital High Vigilance theory below. This could be because of the different setting, focus and/or methodology used by the authors in question. Therefore, the following sections will compare the Hospital High Vigilance substantive theory to the literature found and how the concept of vigilance was mentioned and used in literature in different settings.

6.3.1.1 Vigilance in paediatric/neonatal settings

The term vigilance in paediatric and neonatal settings is prominent in the literature. Seven articles were identified in the search using vigilance as a theme or category but not as a central aspect or concept (Dudley and Carr 2004, Lee and Lau 2012, Kelly and Kelly 2013, Macias et al. 2015, Wernet et al. 2015, Anderson et al. 2018, Sarin and Maria 2019). The prominence of vigilance in paediatric/neonatal settings could be because, in the paediatric population, the parents are expected to be present and be knowledgeable in the context of illness (Kelly and Kelly 2015) and conforming to the healthcare professionals' expectations of them when parenting (Callery and Smith 1991). This high

expectation could eventually increase the state of vigilance by the parents, especially while their child is hospitalised (Dudley and Carr 2004).

Literature in paediatric/neonatal settings focused on the vulnerability of the patient (child) in which the parent acts as an advocate for their child in order to 'safeguard' or protect them (Kelly and Kelly 2013, Anderson et al. 2018, Lee and Lau 2012, Dudley and Carr 2004, Sarin and Maria 2019, Macias et al. 2015, Wernet et al. 2015). Consequently, this was reflected in the definition of vigilance in various studies, which will be compared to the substantive theory. Vigilance is represented as a constant watchfulness of parents both at home and in the hospital when their child is undergoing treatment (Kelly and Kelly 2013). The effects of vigilance to be on the alert for possible side effects of therapy were an increase in the parents' fear, lack of control and lack of ability to plan due to the illness (Anderson et al. 2018). Moreover, constant vigilance represents the mother's (or parents) empathic insight and feelings about caring for their vulnerable, hospitalised sick child (Lee and Lau 2012). On the other hand, vigilance was defined as a caring pattern or expression of families staying with hospitalised relatives (Dudley and Carr 2004). Therefore, the mother needs vigilance to recognise the symptoms and needs of the baby/child because their baby/child cannot voice or point out these symptoms and needs (Sarin and Maria 2019, Macias et al. 2015, Wernet et al. 2015).

This understanding of vigilance as protection or safeguarding of children during hospitalisation by their parents can also be found and reflected in the core category of Hospital High Vigilance theory. The theory in this study was constructed with adults, and the patients (relatives) were autonomous over their care. They were not perceived as vulnerable, but the informal carers were still protecting and safeguarding their relatives (patients). This could be because there were other factors besides the patient's vulnerability in which vigilance could be affected. The literature identified three other factors that influenced the parents' vigilance: knowledge, presence, and power issues (Kelly and Kelly 2013, Wernet et al. 2015).

Literature in paediatric/child settings explains how parents felt confident knowing their child while at home (during a stable phase) and how this changed when the disease manifested, and they went to the hospital (Kelly and Kelly 2013). The

manifestation of the illness made the parents feel insecure, fragile, and unable to care for their child because the parents did not have the knowledge, skills, and experience of the illness and hospital norms (Kelly and Kelly 2013, Wernet et al. 2015). Therefore, this lack of knowledge induced a lot of insecurities in the parents and thus increased their vigilant stance (Kelly and Kelly 2013, Wernet et al. 2015). However, near the end of the child's treatment, the family acquired knowledge about the illness and treatment of their child, which made them more confident and gave them a higher ability to cope (Kelly and Kelly 2013). In contrast, in the Hospital High Vigilance theory, the informal carers have a high level of knowledge about the chronic disease through past experiences. Some informal carers were healthcare professionals, and therefore had a professional level of knowledge as well as intimate knowledge of their relative and the care they should receive, years of experience in taking care of the patients and repeated admission gave an extra depth of insight into this group of carers. However, participants in this study still experienced a high level of vigilance. This could be because a child with an illness that is not chronic could be cured, depending on the severity of the illness. In chronic illness, the disease cannot be cured but only contained. A slight change in health status could dramatically affect the patient and consequently the relationship between the informal carers and their relatives (patients).

The presence of a parent near their child during most of the hospitalisation period is considered essential, acceptable and important by the hospital staff (Kelly and Kelly 2013, Wernet et al 2015). The literature highlighted how this continuous presence of the parent near their child could help the parents by being less vigilant of their child during hospitalisation. Vigilance was characterised by how parents kept children nearby, undertaking a check of the body and repeatedly questioning the child (Kelly and Kelly 2013). Nevertheless, parents still experienced an increase in their vigilant state and anxiety when children were asleep and during the child's illness in hospital (Kelly and Kelly 2013, Wernet et al 2015). Similarly, this increase in the vigilance state was seen in the Hospital High Vigilance theory when the participants had to leave the patient alone for some time because of personal commitments and hospital regulations/norms.

However, power issues were another factor that affected the parents' vigilance while their child was hospitalised. In fact, parents modified their behaviour to try

and be heard (Anderson et al. 2018), especially in cases where healthcare professionals challenged the parents' knowledge on how to take care of the child (Kelly and Kelly 2013, Wernet et al. 2015). Furthermore, mothers adapted to the healthcare professionals' attitude to stay near their children (Lee and Lau 2013). While mothers felt that healthcare professionals were imposing their views and recommendations (Wernet et al. 2015). Consequently, parents experienced increased frustrations, shame, insecurity, and anxiety because the health professionals saw the parents as a helping hand and not as partners in planning their child's care (Kelly and Kelly 2013, Wernet et al. 2015, Lee and Lau 2013). These findings support the core category of Hospital High Vigilance theory which was affected by the continuous struggle in striving towards resilience because of the break in normal resilience due to disempowerment that happened during admission and hospitalisation.

Literature in the paediatric/neonatal setting highlights that although the presence of the parents near their children during admission and hospitalisation is very important, the mere presence is not enough. Therefore, the above literature and the Hospital High Vigilance theory confirm that vigilance can be affected by the patient's vulnerability, informal carers' knowledge, and power issues between the hospital staff and informal carers. The main difference between parents taking care of their children and informal carers taking care of their relatives (patients) in hospital settings is parents are expected to be near their children (Kirk et al 2005, Callery 1995). Whereas informal carers taking care of their relatives (patients) are not expected to do so. Informal carers are expected to leave the care of their relatives (patients) in the hands of the health care professionals (Lowson et al 2013). Despite this difference, both parents in the above body of literature and informal carers in the Hospital High Vigilance theory experience a high sense of vigilance.

However, the Hospital High Vigilance theory adds to the above knowledge other factors that influenced the vigilant state of the informal carers which were not discussed in the above literature, like the unmet needs of the informal carers, the instability of the patients, and the continuous struggle to cope in an emergency and admission. Another explanation could be that informal carers need to be more involved in their care which will be discussed in the below sections.

6.3.1.2 Vigilance in a critical care setting and resuscitation settings

Five articles were identified during the literature search which discussed (although not centrally) vigilance of the informal care when the patient was unstable or in a critical situation (Bjork et al. 2019, Almerud et al. 2007, Halm and Nasseff 2005, Bradley et al. 2017, O'Connell et al. 2017). This comparison is made because informal carers in the Hospital High Vigilance theory experienced admission of their relatives (patients) in a critical care setting or a resuscitation setting and were in a critical situation. Therefore, the Hospital High Vigilance theory will be compared to how the literature discusses vigilance when the patient is in a critical or unstable state.

Literature exploring carers and vigilance in the critical care and resuscitation settings evolves around the notion of instability of the patient, which eventually affects the care of the informal carers in those situations (Bjork et al. 2019, Almerud et al. 2007, Halm and Nasseff 2005, Bradley et al. 2017, O'Connell et al. 2017). Vigilance by family members in an intensive care context was given two distinct connotations: watchfulness (or presence) and waiting (Bjork et al. 2019). Watchfulness was described as the family members' vigilance over the relatives by being physically present in the intensive unit (Bjork et al. 2019), whereas waiting (outside the department) was defined as living in limbo, feeling helpless and powerless, hoping, enduring, and fearing the worst (Bjork et al. 2019). This is important because informal carers strive to be near their relatives when they are unstable. However, sometimes they have to wait outside the ward/unit (for various reasons) and therefore cannot be near their relatives (Bjork et al. 2019). The consequence of this was the feeling of helplessness and powerlessness when hospital staff decided when informal carers could see their relatives or were asked to wait in the waiting area (Bjork et al. 2019). These definitions of vigilance conform with the core category of the Hospital High Vigilance theory. The patient's instability in an emergency situation eventually exacerbated the vigilant stance of the informal carers in this study. What is different, in the present study, however, is that rather than having two words (watchful and waiting), it is conceptualised as one word - watchful waiting because the informal carers had to leave their relatives alone not only when asked by the hospital staff but because they had other personal commitments (work or family) which they could not refuse to attend. Furthermore, watchful waiting is the act of waiting to be near their relatives and phoning the ward, not

switching the phone off, not engaging in social activities, and leaving someone else near their relatives while they were away. This is because the informal carers were eagerly waiting to be near their relatives, but at the same time, they watched over them even if they were not physically near them.

The presence of the informal carer near the patient was given prominence in the literature that affected the vigilant state of the informal carers. Vigilance was associated with the informal carers' presence as beneficial not only for the patient but even for the informal carers (Bradley et al. 2017). In the study conducted by O'Connell et al (2017) vigilance was conceptualised from the themes – 'the choice to be there is my right', 'there are limitations to my being there', 'it gives me comfort and peace of mind', and 'it comforts my child and comforts me'. This confirmed the importance of having family presence nearby (in a resuscitation situation or a critical care setting), of not being alone or dying alone during that particular moment (Bradley et al. 2017, O'Connell et al. 2017). This mimicked what the participants in the Hospital High Vigilance theory co-constructed as separation anxiety. Furthermore, the above concepts from the literature reinforce the notion of the informal carers' needs. However, Bradley et al. (2017) state that only half of the patients that participated in their study (52%) wanted their informal carers near them in these situations. This contrasted heavily with O'Connell et al. (2017), who found that 94% of the mothers wanted to be near their child during resuscitation. Furthermore, all the Hospital High Vigilance theory study participants wished their family would be present during their acute illness episode. However, this must be taken with caution as the interviews were conducted with the informal carers and their respective relatives (patients) together. One could argue that the presence of the informal carer (the one that provides most of the patient's care) could have affected the response to not hurt this sole care provider. Furthermore, O'Connell et al. (2017) found that as the mother was legally responsible for the child, it was acceptable to the hospital staff to have the mother near her child. On the other hand, one must point out that Bradley et al. (2017) conducted a study on patients who did not experience resuscitation, and therefore, the results were based on what patients imagined what would be felt and thought if they experienced a resuscitation situation. Living the experience could have given participants different perceptions and, consequently, a different response.

The presence of the informal carers near the patients was vital because it could reduce the fear and anxiety of the informal carers by removing doubts on the treatment given to the patient, reinforcing that everything possible was being done and sustaining connectedness and bonding in the patient–family relationship (Halm and Nassef, 2005), which conforms to the notion that presence could meet the needs of informal carers' symbiotic relationships in the Hospital High Vigilance theory. The presence of family near the patient was significant, but the family still experienced anxiety and fear (Halm and Nassef, 2005). The notion of this ambiguity is that although patients are in an environment (hospital setting and intensive care) in which the patient was constantly being monitored and observed by hospital staff, higher staffing levels and advanced technology, the patients and the informal carers still felt not seen and as being invisible (Almerud et al. 2007). This ambiguity contributed to the notion of confrontation with death as an increase in fear of dying (Almerud et al. 2007). Although being in a hospital setting, this ambiguity of the informal carers still experiencing a high state of vigilance was also reflected in the Hospital High Vigilance theory. The notion of constant watchfulness, invisibility, harm avoidance, and advocacy was noted during admission and hospitalisation. Furthermore, the above could explain the disempowerment component of the theory by staff not letting the informal carers near their relatives. This resulted in striving to be resilient and could affect the symbiotic relationship between the informal carers and the relatives and even the vigilance state of the informal carers. Another possible explanation could be the uncertainty the informal carers experienced during their relatives' unstable and emergency phase, which will be expanded in Section 6.3.2.

6.3.1.3 Hospital High Vigilance theory and Family Centred Care Theory

Therefore, the above concepts and the concepts in Section 6.3.1.1 confirmed the importance of the informal carers' physical presence near their relatives (patients) during admission and hospitalisation. This is because the relatives (patients) will be in a critical and unstable situation where informal carers being near their relatives is essential to both the patient and the informal carers. However, the mere presence of the informal carers near their relatives (patients) is not enough. This presence will help not only the patient but even the informal carers. The Hospital High Vigilance substantive theory confirmed that the presence of informal carers near the patient only was not enough. Still, there are other factors that healthcare professionals need to consider helping informal carers during

admission and hospitalisation. The hospital staff need to involve and tailor the interventions, including the informal carers and the patients. In view of this, the Hospital High Vigilance theory is compared to the Family-Centred Care (FCC) theory (Nethercott 1993) to answer this gap identified in the above literature. Furthermore, this was deemed necessary because it is one of the theories most widely mentioned and used to help healthcare professionals, including the family in care.

FCC can be defined as a concept and practice-theory (Hutchfield 1999), a holistic approach (Stower 1992), a model of care (Shields et al. 2007) or a paradigm (Mikkelsen and Frederiksen 2011). Despite its widespread usage and supported through literature and practice, FCC can be difficult and ambiguous to understand and implement in practice (Hutchfield 1999, Kuo et al. 2012). This is because there is a lack of consensus on the meaning and the concepts of FCC in different context (Kuo et al. 2012). There is not even a consensus on who originally coined the term and the model FCC – literature in the USA widely use Sheldon's et al. (1987) concept of the model, while in UK literature mention Nethercott's (1993) concept analysis of the FCC (Hutchfield 1999). This increased the confusion and the ambiguity of using the FCC in practice (Mikkelsen and Frederiksen 2011). According to Mikkelsen and Frederiksen (2011), this confusion could be attributed to the gap between the theory, practice and research in FCC. Therefore, it is pertinent to examine the FCC model in conjunction with the High Hospital Vigilance theory that could address this gap. However, for the purpose of this study, the understanding of FCC will be based on the concept analysis of Hutchfield (1999), who based his research on both Nethercott's (1993) and Sheldon et al. (1987) works, amongst others.

According to Hutchfield (1999), the centrality of an FCC model is on the relationship between the family and the nursing. This relationship will be built on respect for the family and honest and open communication. This will enhance cooperation, collaboration and negotiating care. Hutchfield (1999) described the above concepts hierarchically, starting with involvement, to participation, through partnership, culminating in family-centred care. Compared to the Hospital High Vigilance theory, it seems that the informal carers are shifting between involvement and participation rather than family-centred care. The notions of cooperation, collaboration and negotiated care are not evident. This is because,

as seen in the disempowerment component of the Hospital High Vigilance theory, the informal carers were seen as emotional support for the patients, minimal participation in routine care is enhanced, and the communication between the health care professional and the informal carers is emphasised only on information giving about the previous condition of the patient (see section 5.5.1.3). Although the new substantive theory highlights a rapport between the informal carer and the health care professionals in some instances, there is no equal status or mutual respect. The consequences of this evolved in a high emotional state of vigilance of the informal carers during admission and hospitalisation.

An issue identified in the above conceptualisation of Hutchfield (1999) FCC is the provision for support needed for the parents in their role. This support was required to give adequate care to the patients and let the parents sufficient rest during stressful moments such as admission and hospitalisation. This was not the case as most parents were often reluctant to leave their sick children (Hutchfield 1999). This is corroborated in the Hospital High Vigilance theory whereas through the components of difficulties in gaining access and separation anxiety, it identified barriers in preventing the informal carers to leave their relatives (patients) 'alone'. Some informal carers were reluctant to let go of their relatives (patients) in the hand of the health care professionals due to various issues highlighted in chapter 5. Thus, they were not being resilient, increasing their vigilance state. Moreover, the struggle to cope or strive towards resilience affected the symbiotic relationship between the informal carers and the relatives (patients). This increased the informal carers' unmet needs and increased the vigilance stance.

However, Hutchfield (1999) questions the relevance of implementing FCC in all circumstances or conditions. This is because the hierarchy model of Family Centred care presented by Hutchfield (1999) emphasises that medical care should be parent-led through mutual respect and involvement of the family. This is because the parents have extensive knowledge of the child's illness and treatment which the hospital staff acknowledges (Hutchfield 1999). The notion of parent-led medical care could impose a controversy because, as stated in section 6.3.1 parents are expected to be near their children and be involved (Kirk et al. 2005, Callery 1995). Whereas informal carers taking care of their relatives

(patients) are not expected to do so. Informal carers are expected to leave the care of their relatives (patients) in the hands of the health care professionals (Lowson et al 2013). One can argue that healthcare professionals and families often bring different perspectives to the care (Lawlor and Mattingly 1998). Furthermore, traditionally healthcare professionals are viewed and considered the expert and assume an authoritarian role of expert over the patient and the relatives (Lawlor and Mattingly 1998). Moreover, as seen in the intuitive component of the new substantive theory, even with extensive knowledge of the illness by the informal carers (some were healthcare professionals themselves), they still experienced a high vigilance state. The informal carers in the Hospital High Vigilance theory showed a high degree of knowledge about their relatives through years of caring and even through their symbiotic relationship with the patient. However, this was not consistently recognised by healthcare professionals. Therefore, the understanding and application of Hospital High Vigilance theory, which explains the world of the informal carer while taking care of a patient during admission and hospitalisation, could help better implement Family-Centred care in practice. However, one must keep in mind that the informal carers and the patient must be viewed in their context when implementing the FCC model. The Hospital High Vigilance theory could help in giving this context to the implementation of the FCC model.

In the Hospital High Vigilance theory, the informal carers struggled to be near the patient; however, being near them was insufficient. The informal carers wanted to be involved in the care of the patients. They did extraordinary things (ignoring themselves, ignoring others, spending a lot of time near the patient, obsessively thinking about the patient). Still, they felt diminished by not being recognised and their knowledge not accepted by the healthcare professionals. Eventually, the above resulted in striving towards resilience and affected the symbiotic relationship, resulting in a high vigilance level. Therefore, the Hospital High Vigilance theory presented in this thesis could eventually help implement the FCC theory in context by adding new knowledge and explaining other factors that could hinder or help the presence and participation of the informal carer in decision-making and care of the patient.

6.3.1.4 Vigilance in the oncology/end-of-life setting

In this section, a discussion about how vigilance has been used in an oncology/end-of-life setting will be explored. Two articles were identified during the literature search, which connected vigilance and the informal carers during hospitalisation in an end-of-life setting (Cohen et al. 2010, Cronin et al. 2015). Literature and concepts in this area revolve around intense emotions and feelings, specifically about fear of death of their relatives or separation. In fact, due to this fear, informal carers of hospitalised end-of-life patients increased their daily hours and duration of time near the patient as an act of vigilance over their relatives (Cohen et al. 2010). This corroborates what the informal carers experienced in Hospital High Vigilance theory when they increased their hours and presence near their relatives (patients) and had separation anxiety when leaving their relatives 'alone' in hospital. The concept around family caregiving of hospitalised older adults at the end of life focuses mainly on what burdens the informal carer in an end-of-life situation (Cohen et al. 2010, Cronin et al. 2015). In the Hospital High Vigilance theory, the concept evolved around the care given as being their duty, especially during hospitalisation, and not being a burden. This was further reflected in the participants' accounts, which never said 'burden' but always 'duty'. In other words, it was their responsibility to be near the patient during admission and hospitalisation in which they did it willingly rather than being imposed or loaded on them. This difference could be partly due to methodological differences between the studies (Cohen et al. 2010 used cross-sectional survey designs, while this thesis used grounded theory methods). Another difference could be the researcher's background as an informal carer and healthcare professional. It could be that a different researcher, with a different background, experiences, and perceptions, and participants in various settings with diverse backgrounds and experiences, could interpret and co-construct the data in another way that is not duty (Charmaz 2014). Duty was reflected in the Hospital High Vigilance theory: the participants exhibited a high level of commitment, which resulted in long hours near the patient, bargained their way near the patient, and exhibited constant watchfulness. Eventually, this resulted in emotional turmoil and separation anxiety, resulting in a higher state of vigilance.

Another aspect of vigilance in providing nursing care for patients at the end of life was providing the family with a sense of being cared for and easing their uncertainty and anxiety (Cronin et al. 2015). The input of the hospital staff could

be interpreted as the empowerment of the informal carers (Cronin et al. 2015). On the other hand, the Hospital High Vigilance theory examined the effect of the staff's attitude and the routines of the hospital which in turn led to a disempowerment on the informal carers, which resulted in the continuous struggle to cope (striving towards resilience). However, even if some informal carers were not disempowered, they still felt discomfort and fear leaving the patient alone; one primary reason was being afraid of their relative dying alone (Cronin et al. 2015). This is because the informal carers still had to leave the patients 'alone'. After all, they could not be present all the time. The Hospital High Vigilance theory adds to the above knowledge because it explored this notion of informal carers leaving their relatives' bedside and was conceptualised as separation anxiety and duality which prevented them from coping and thus increased their vigilance stance. Furthermore, end-of-life decision-making was challenging for the informal carers; some expressed the concern that they were going against their relatives' wishes (Cronin et al. 2015). This was corroborated in the Hospital High Vigilance theory. There was a delay in seeking help during the admission due to status quo bias in the break-in-life trajectory notion, which will be further discussed in the below sections.

6.3.1.5 Vigilance of informal carers of cognitively impaired persons

This section will explore and compare the Hospital High Vigilance theory with vigilance of informal carers of cognitively impaired populations. Although participants (patients) with cognitive impairment were excluded in this thesis, it is interesting to compare how the Hospital High Vigilance theory differs or is similar. Informal carers of cognitively impaired persons tend to be constantly on the alert, especially in the hospital settings (Mahoney 2003, Gibbs et al. 2008, Givens et al. 2012). The literature on vigilance in cognitively impaired persons focuses on advocacy and vulnerability, reflected in the definitions of vigilance in the Hospital High Vigilance theory.

Vigilance was conceptualised as the caregiver continually overseeing the patient's activities to prevent harm, with five key components: watchful supervision, protective intervening, anticipating, always on duty, and being there (Mahoney 2003). Furthermore, the informal carers' vigilance on cognitively impaired persons was needed as some changes in a person's behaviour, such as quietness and withdrawal, may be as significant as an outwardly directed

behavioural disturbance (Gibbs et al. 2008). This vigilance was conceptualised: feeling notably fearful and anxious, communication, practicalities of being in or attending hospitals, discrimination and negative comments, and behaviour problems (Gibbs et al., 2008). Another aspect of vigilance was the need to remain vigilant by the family member to attend and prevent lack of care in the patients/residents' hygiene which includes concepts like inadequate resident personal care resulting in family member vigilance and participation of care; stress at the time of the nursing- home admission; lack of communication with physicians and challenges of surrogate decision-making (Givens et al. 2012). Although the participants (patients) in the present study had no cognitive disability, the above literature definition of vigilance is similar to the Hospital High Vigilance theory. Participants identified concepts like careful watching for possible danger or difficulties during admission and hospitalisation. Participants continued to describe how they watched the patient's health status and behaviour to prevent harm (bedsores, infections and death).

Adequate communication between the informal carers and hospital staff was identified in the literature as the vital element to alleviate the informal carer's stress, especially in patients with cognitive impairment (Gibbs et al. 2008, Givens et al. 2012). However, as in the neonatal/paediatric literature, informal carers' vigilance is affected by the patient's vulnerability and other factors. The informal carers did not feel listened to by the hospital staff, particularly during admission (Gibbs et al. 2008). Informal carers expressed that because of a lack of communication by the hospital staff, they were essentially unable to act as the patient's advocate and engage in shared decision-making (Givens et al. 2012). Furthermore, stress, guilt, fear, and anxiety were the most commonly described emotions about the cognitively impaired population in the literature. These feelings are derived from the informal carers' past experiences (mainly negative), repeated admissions and unwanted admissions (Gibbs et al. 2008, Givens et al. 2012). Hospital admission and discharge procedures were seen as a burden and cumbersome to the informal carers taking care of a patient with cognitive impairment (Gibbs et al. 2008). Eventually, the stress, guilt, fear and anxiety increased the vigilance state of the informal carers (Mahoney 2003, Gibbs et al. 2008, Givens et al. 2012). Furthermore, these feelings and concerns exacerbated when they left their relatives alone in the hospital (Gibbs et al. 2008). Mahoney

(2003) continued to discuss that carers could never let go of their overseeing responsibilities even during the night or during hospitalisation when their contact time will be reduced. Some informal carers suggested that having a sitter when they rested could help alleviate their stress (Mahoney 2003). Furthermore, the informal carer's unique knowledge anticipated what might happen to their relatives (Mahoney 2003, Gibbs et al. 2008).

This confirms and supports the core category of Hospital High Vigilance theory, and the related components which are constantly affected by each other. The Hospital High Vigilance theory is composed of a distinct social process that the healthcare professionals could use to identify what is happening during admission and hospitalisation. Thus, this will help healthcare professionals devise holistic interventions for every informal carer. Furthermore, the Hospital High Vigilance theory could add to the notion that the informal carer and their relatives must be assessed and treated as dyads because they are connected and depend on each other (symbiotic relationship).

6.3.1.6 Vigilance in the acute care setting – comparing Hospital High Vigilance theory with family vigilance theory

This section will compare how vigilance was used in different acute care settings. The Hospital High Vigilance theory was developed in the context of informal care of a patient with chronic heart failure during admission and hospitalisation (acute care). Eight articles were identified that addressed the concept of vigilance in acute areas, mainly acute medical and surgical units, acute neurology and neurosurgical units, inpatient rehabilitation units, renal units and acute oncology settings, but they did not address patients with CHF (Carr and Clarke 1997, Carr and Fogarty 1999, Rainey et al. 2013, Carr 2014, Khabarov et al. 2015, Ambrosi et al. 2016, Kim et al. 2018, Kaya and Turan 2018).

Many similarities were seen between the Hospital High Vigilance theory and how vigilance was described and conceptualised in the literature of the acute care setting. One of the main convergences between the literature and the Hospital High Vigilance theory was the theory of Family Vigilance (Carr and Clarke 1997, Carr and Fogarty 1990, Carr 2014). The family vigilance theory was developed through three ethnographic studies conducted in acute care neurology, an inpatient rehabilitation unit, and an oncology unit between 1997 and 1999 (Carr and Clarke 1997, Carr and Fogarty 1990, Carr 2014). Twenty-six informal carers

participated in the above ethnographic studies, which used interviews and observations as data collection methods.

It is essential to note the methodological differences that were present in the studies conducted by Carr and Clarke (1997), Carr and Fogarty (1990) and Carr (2014), and the research conducted to construct the Hospital High Vigilance theory presented in this thesis. The focus of the studies undertaken to develop the Family Vigilance theory (Carr 2014) focused on the concept of vigilance from the beginning, whereas the starting point of this thesis was more open and broader (see Chapter 2), and vigilance was not mentioned or looked for. The core category of vigilance in the Hospital High Vigilance theory arose from data (see Chapter 3 and Chapter 4). However, Carr and Clarke (1997) used open-ended questions (similar to this thesis) that were very general. Still, no indication was given on how the personal ideas and experiences of the authors could have affected data collection and analysis. Compared to this thesis, the studies mentioned above (Carr and Clarke 1997, Carr and Fogarty 1990, Carr 2014) were conducted in different countries (USA vs Malta), in different settings, and with different disease diagnoses. Another difference noted was that the informal carers in the Family Vigilance theory studies were those who stayed all the time with the patient during the hospital admission. At the same time, this thesis included those informal carers who had an allocated time to visit the patients due to the hospital policies. Interviews and observations in the above studies were conducted while the informal carers were hospitalised, while in this thesis, the interviews were done after the discharge of the patients. These studies included only the informal carers, while this thesis included both the informal carers and the patients.

The above highlights that although substantial differences exist between the above studies and this thesis, the two theories were comparable. The three studies resulted in a theory consisting of vigilance as the central concept and five main themes – a commitment to care, resilience, emotional upheaval, dynamic nexus, and transition (Carr and Clarke 1997, Carr and Fogarty 1990, Carr 2014). These five themes will be discussed and compared to the conceptual categories of the Hospital High Vigilance theory.

The first theme of the Family Vigilance theory was described as commitment to care which was defined as the need to protect the patient, a want to be involved, and watching for changes in the patient's condition, and was characterised by a feeling of love, advocacy, and vulnerability (Carr and Clarke 1997, Carr and Fogarty 1990, Carr 2014). Informal carers in these studies described how after many years of being in a relationship, they did not want to leave their relative alone, and so stayed near their relatives all the time (Carr and Clarke 1997). These concepts confirm the importance the informal carers gave to their relationship with their relatives and how much they valued their intimacy during their long-standing relationship with the patient. This could be easily compared to a break in the symbiotic relationship during admission and hospitalisation in the symbiotic relationship component of the Hospital High Vigilance theory. This symbiotic relationship in the Hospital High Vigilance theory was based on the long-term relationship between the informal carer and their relatives. The Hospital High Vigilance theory adds to the above knowledge by giving a more in-depth meaning of the relationship between informal carers and patients (symbiotic relationship) and how this evolved or changed during admission and hospitalisation. This difference could be the case because in the Hospital High Vigilance theory, the patients were suffering from chronic illness with years of admissions and hospitalisations. In contrast, the patients in the family vigilance theory (Carr 2014) were healthy before being admitted, since they experienced a sudden illness. Furthermore, participants in the literature above described how they did not feel comfortable leaving their relatives alone at the hospital (Carr and Clarke 1997). A possible explanation was because the patient was vulnerable, and the informal carer was the patient's advocate (Carr and Clarke 1997, Carr and Fogarty 1990, Carr 2014). However, the Hospital High Vigilance theory adds to the above knowledge by examining the notion of a break-in-life trajectory vis-a-vis status quo bias, and losing control of the situation, which was not explored in the above literature.

Resilience in the Family Vigilance theory was characterised by how the family members care for themselves, preserving and maintaining a feeling of hope (Carr and Clarke 1997, Carr and Fogarty 1990, Carr 2014). The authors explored the importance of how the informal carers needed to take care of themselves to be near their relatives and be resilient and therefore be vigilant over their relatives

(Carr and Clarke 1997, Carr and Fogarty 1990, Carr 2014). Furthermore, despite being worried, resilience was seen as an encouragement to their relatives to get better (Carr and Clarke 1997, Carr and Fogarty 1990, Carr 2014). As discussed in Section 6.3.2, resilience is essential for informal carers to cope in a difficult situation as in an emergency, admission and hospitalisation. However, where Hospital High Vigilance theory differs from the above studies is that the informal carers' ability to bounce back was affected by other issues like separation anxiety, duality, disempowerment, gaining access (difficulties) and intuitive knowledge, which were not covered in the above studies data. Therefore, the concept of resilience in the Hospital High Vigilance theory focused on the negative aspects preventing resilience and increasing vigilance, rather than on the positive effects of resilience. This adds to the originality and uniqueness of the Hospital High Vigilance theory.

In the Family Vigilance theory, the emotional upheaval was described as the informal carer's emotions (anxiety and uncertainty) and difficult decisions (life and death decisions) they encountered during their experience; in fact, it was conceptualised as living with a loss (Carr and Clarke 1997, Carr and Fogarty 1990, Carr 2014). Furthermore, the Family Vigilance theory saw the future as a loss of normality, whereas in the Hospital High Vigilance theory, due to the break-in-life trajectory and the fear of losing the symbiotic relationship, the participants view no future and do not think about their future (see Chapter 5). This difference between the two theories could be explained because the informal carers in the literature experienced a normal lifestyle (i.e., without disease) before their relatives experienced a catastrophic event like cerebral bleeding, which changed their normal lifestyle. Participants (informal carers) in the Hospital High Vigilance theory were already taking care of their relatives suffering from CHF, and informal carers were used to recurrent admissions and hospitalisation. However, every break in their life trajectory (admission) could mean a sudden abruption of their symbiotic relationship (i.e., death of the patient) due to possible complications.

The Family Vigilance theory discusses a transition phase in which a change in the family member's lifestyle, roles, daily rhythm, comfort, and space was noted by embracing the new role of informal carers (Carr and Clarke 1997, Carr and Fogarty 1990, Carr 2014). In contrast, participants in the Hospital High Vigilance theory had already been informal carers for a long time due to the patient's

chronic illness. Therefore, Family Vigilance theory was about becoming an informal carer, whereas in the Hospital High Vigilance theory informal care was already established. Like the Family Vigilance theory, the Hospital High Vigilance theory conceptualised how an admission (a break-in-life trajectory) interrupted the informal carer's and their relative's lifestyle or routine, role relationship, routines, and assumptions (this notion will be expanded more in section 6.3.5). However, what is different is that the Hospital High Vigilance theory participants did not embrace and perceive admission and hospitalisation as a change and growth but rather a break in their normal chronic routine and thus a break in their symbiotic relationship. This is important because by recognising that informal carers strive to go back home as soon as possible, the healthcare professionals could involve the informal carers at a very early stage and recognise them as informal carers. On the other hand, healthcare professionals should not mistake this enthusiasm to take home their relatives as an excuse to discharge the patient early.

Dynamic nexus in the Family Vigilance theory described the importance of the current support systems and how informal carers negotiate the change in their relationship with family, friends and healthcare providers (Carr and Clarke 1997, Carr and Fogarty 1990, Carr 2014). This was perceived as problematic and extremely hard to deal with (Carr and Clarke 1997, Carr and Fogarty 1990, Carr 2014). This corroborated with the notion of striving towards resilience in the Hospital High Vigilance theory in which duality and disempowerment prevented the informal carer from coping in a stressful environment like the hospital. However, what the Hospital High Vigilance theory adds to the above is the notion of past experiences. Thus, intuitive knowledge helped or hindered the vigilance state of the informal carers. A reason could be that the informal carers in the Family Vigilance theory were new to the informal carers' world and thus did not acquire the necessary skills and knowledge that participants in the Hospital High Vigilance theory had developed during years of caring. On the other hand, the Family Vigilance theory does not explain the informal carers' difficulties in being near their relatives. Gaining access (difficulties) in the Hospital High Vigilance theory was co-constructed as the informal carers' difficulties in continuing their symbiotic relationship during admission and hospitalisation. This was because of various hospital rules, norms and regulations which prevented access to their

relatives. In the studies conducted to build the Family Vigilance theory, the policy was that the informal carers were always allowed near their relatives, and informal carers who only visited their relatives during hospitalisation were omitted (Carr and Clarke 1997, Carr and Fogarty 1990, Carr 2014). Carr (2014) stated that 15 of the 26 informal carers spent 24 hours a day with their relatives, while others spent fewer hours but had unlimited access to their relatives. This difference in criteria for recruiting the participants in the study could be the cause of this difference. However, in my experience, most informal carers could not be near their relatives 24 hours a day during hospitalisation due to personal commitments as expressed in the duality component of the Hospital High Vigilance theory. Different hospitals (sometimes even different wards in the same hospital) have different visiting hours and family presence policies. Therefore, the Hospital High Vigilance theory could help the healthcare professional identify these barriers in preventing the access of the informal carers and devising actions to help the informal carer gain access.

Besides the above theory, other themes and concepts were found that addressed vigilance in acute settings (Rainey et al. 2013, Khabarov et al. 2015, Ambrosi et al. 2016, Kim et al. 2018, Kaya and Turan 2018). Vigilance in the context of waiting outside a hospital unit was affected by the notion of gaining knowledge (Kim et al. 2018). This was further expanded in the theme 'sharing information and consoling' where the informal carers learned their knowledge through long-term experiences with the patient (Kim et al. 2018). Some informal carers looked forward to going in the waiting area while their relatives used the treatment time to relax (Kim et al. 2018). However, the same informal carers still experienced insecurities, nervousness, and uncertainty while waiting (Kim et al. 2018). This was because they had had bad experiences during the treatment of their relatives (Kim et al. 2018). Therefore, the informal carers increased their vigilance by checking on the patients, especially during treatment initiation and termination (Kim et al. 2018). This supports the notion of knowledge or intuitive knowledge, and separation anxiety could affect the ability to cope during admission and hospitalisation, thus increasing the vigilant state of the informal carers as stated in the Hospital High Vigilance theory. However, the above literature did not explain or explore how knowledge and separation anxiety could affect the relationship between the informal carer and the relatives.

Another aspect of vigilance evolves around the sub-theme of collaboration. The informal caregivers' background knowledge about their relatives was essential to help the nurses care for the patient (Khabarov et al. 2015). The informal carer did not connect with hospital staff, resulting in being submissive by not asking essential questions (Khabarov et al. 2015). Data from the Hospital High Vigilance theory recognised nurses' importance for patients and informal carers, but the informal carers were frustrated when ignored (disempowerment) (Khabarov et al. 2015). In congruence with the symbiotic relationship in the Hospital High Vigilance theory, Khabarov et al. (2015) described the hidden realities of families and caregivers by the importance of being present and mediating wellness. The informal caregivers pointed out that their relatives would not recover entirely without their daily input. Furthermore, some patients relied heavily on them, so much that they did not seek nurses' help (Khabarov et al. 2015). This supports the notion of the symbiotic relationship in the Hospital High Vigilance theory, which points out the importance that informal carers have when the healthcare professionals could have imposed disempowerment.

Furthermore, this symbiotic relationship and, consequently, vigilance evolves on the notion of the presence of the informal carer, especially during admission and hospitalisation. Most of the patients valued the presence of the informal carers, especially during an invasive procedure (Kaya and Turan 2018). However, as seen in other sections of this chapter (see sections 6.3.1.1, and 6.3.1.2), the mere presence of the informal carer near the patient was not enough to lessen the anxiety and stress of the informal carer and thus being less vigilant. The more critical the patient, the more hours informal carers spent near their relatives, which can indicate high levels of vigilance because of the vulnerability of the patient (Ambrosi et al. 2016). Therefore, vulnerability and instability of the patient during admission and hospitalisation directly influenced the presence of the informal carer near their relatives and thus increased the vigilance state.

Another aspect of vigilance was based on the level of information and experience, power issues and the relationship of the informal carers and patient. The ability to recognise changes in the clinical condition stated that patients were sometimes not aware of their deterioration because of sensory impairment or reduced level of consciousness (Rainey et al. 2013). This placed the patient in a very vulnerable state. They needed to rely on the healthcare professionals or the relatives to

detect and respond appropriately to changes in their clinical conditions (Rainey et al. 2013). In such cases, the relatives were identified as essential to speak up on the patient's behalf during admission and hospitalisation (Rainey et al. 2013). Relatives who are not medically trained relied on their previous experiences of acute illness to identify symptoms that indicated conditions were deteriorating (Rainey et al. 2013). The relatives and patients built confidence and trust through their knowledge to recognise the deterioration of the patient (Rainey et al. 2013). This involved a long relationship between the informal carers and hospital staff because of the chronic illness and repeated admissions, but also self-monitoring, when the relatives were sometimes not recognised as equal partners by the healthcare professional (Rainey et al. 2013). Furthermore, relatives were even ignored when they spoke up against a discharge of their relatives because, in their opinion, their relatives were not well enough to be discharged (Rainey et al. 2013). Restricting contact time due to visiting times, work and family commitments, and lack of knowledge are described as the major factors for the relatives to recognise deterioration of the patient (Rainey et al. 2013). These restrictions led to the anxiety of the informal carers (Rainey et al. 2013). The above supports the notion that when the patient is unstable, the informal carer's struggle to cope and the relationship between informal carers and their relatives result in a higher vigilance state. The Hospital High Vigilance theory aimed to address the above effects by identifying the social processes involved in informal care during admission and hospitalisation.

Therefore, the above discussion confirms that the relationship between the informal carers and their respective relatives is valued and vital to both parties. However, the concept of symbiotic relationship in the Hospital High Vigilance theory described the connectedness of the informal carers and their respective relatives. It explained the needs of the informal carers and how these needs are affected in the context of admission and hospitalisation. Examining the relationship between the informal carer and their respective relatives could help to better understand what is happening, especially during admission and hospitalisation.

6.3.2 Hospital High Vigilance in context of uncertainty

This study focuses on the informal care of patients who suffers from a chronic illness (chronic heart failure). Any illness can be ambiguous, complex, and

unpredictable, increasing uncertainty (Clayton et al. 2018, Mishel 1988). Uncertainty is defined as 'the inability to determine the meaning of illness-related events' (Clayton et al. 2018, p. 49). An illness-related event could be an admission and hospitalisation after a sudden exacerbation of CHF symptoms. Therefore, as a possible reason and understanding why the high vigilance response was co-constructed in theory, it is helpful to analyse the concept of uncertainty in conjunction with vigilance. A concept analysis of uncertainty in illness reviewed various factors associated with and characterising uncertainty, including:

- Ambiguity – more than one meaning
- Inconsistency – incompatibility or discordance
- Vagueness – lack of detail, imprecision, not definitive or clear
- Unpredictability – an inability to make statements about future events
- Lack of information – associated with uncertain situations
- Unfamiliarity – difficult to prevent and categorise a situation or event

(McCormick 2002, p. 128–129)

The above definitions and the Hospital High Vigilance theory highlighted and supported chronic illness's unpredictability during admission and hospitalisation. This evolved in the informal carers being in a state of highly vigilant, with the ambiguity of being vulnerable, present, constantly watchful, watchfully waiting, an advocate, dutiful, caring, invisible, lacking control, losing dignity, and avoiding harm, all while the patient was being cared for in a complex environment such as a hospital. This evoked an emotional response of high vigilance. A possible explanation of this high vigilance state could be the uncertainty that the informal carers experienced during admission and hospitalisation of their relatives during a sudden onset, instability, and exacerbation of chronic illness symptoms. The Hospital High Vigilance theory shows how the informal carer during admission and hospitalisation of their relatives experienced high vigilance which spread from the illness of their relatives to other areas of the informal carers's personal life (duality, unmet needs) and competed with the informal carer's previous mode of functioning (symbiotic relationship and normal resilience). This could be compared to chaos theory (Prigogine and Stengers, 1984), which emphasises a system with disorder, instability, diversity, disequilibrium, and restriction

eventually evolving into a healthy system variable. As seen in the Hospital High Vigilance theory, the uncertainty of the informal carers during admission and hospitalisation of their relatives derived from a pattern of disruption (admission) occurring (a break-in-life trajectory, a break in a symbiotic relationship and a break in normal resilience), increased a sense of uncertainty (emotional turmoil), generated more tension, and exceeded a person's level of tolerance (vigilance).

The Uncertainty in Illness theory (UIT) and the Reconceptualised Uncertainty in Illness theory (RUIT) draw from these concepts to explain how a patient or family with enduring uncertainty emerges with a new view of life, adapts or functions, or returns to the previous state of being (Mishel 1981, 1988, 1990). The model of UIT explains how patients and families 'cognitively structure a schema for the subjective interpretation of uncertainty with the illness' (Clayton et al. 2018, p. 49). It consists of three major themes: antecedents of uncertainty, appraisal of uncertainty, and coping with uncertainty (Clayton et al. 2018). RUIT adds other concepts of self-organisation and probabilistic thinking. The emergent substantive theory of this study conceptualises the complex and unpredictable nature of the chronic illness, especially during admission and hospitalisation, as a high vigilant state. Furthermore, these two models directly link vigilance and hypervigilance with the uncertainty of a person or individual experience. From inception, these two models were used in various contexts such as chronic illness, HIV, mental issues, cancers, transplants, and paediatric intensive care (Clayton et al. 2018).

To highlight the connection between uncertainty and vigilance, it is helpful to examine the concepts of the UIT and RUIT in conjunction with the Hospital High Vigilance theory. The antecedent theme incorporates three concepts: the stimuli frame (symptom pattern, event familiarity and event congruence), cognitive capacity (the ability to process information), and structure providers (the resources available to assist in the interpretation of the stimuli frame) (Mishel 1981, 1988, 1990). The appraisal theme incorporates a process of placing values on the uncertain event or situation as either danger or opportunity using inference or illusion. In making sense of an uncertain situation, a person will evaluate/appraise the situation as a danger or opportunity, enabling the individual to mobilise strategies for managing it. The coping theme in the UIT and RUIT

highlights the problem-focused and emotion-focused strategies to manage and cope with the uncertainty.

The component of loss of control in the Hospital High Vigilance theory could be attributed to a high degree of uncertainty, with the two being mutually inclusive and affecting each other. This is because the more an individual feels a loss of control, the more uncertain they may feel. The degree of uncertainty will, by extension, influence the feeling of uncertainty (McCormick 2002). However, being out of control is an emotional response to a situation. In contrast, the person struggles to regain the lost control, increasing the chance of feeling helpless or under stress (McCormick 2002, Mishel 1990). This will eventually become a part of a continuous cycle of appraisal and reappraisal, a component of the UIT and RUIT (Mishel 1990). According to the UIT and RUIT, uncertainty is viewed as either danger or opportunity based on that appraisal. In the Hospital High Vigilance theory, the loss of control and thus uncertainty was viewed as a danger rather than an opportunity. This is because the outcome of the informal carers' relatives while hospitalised was unknown (recovery, further deterioration or death). This resulted in an emotional response of high vigilance, which was described as a coping mechanism to reduce uncertainty, anxiety, and stress (Mishel 1988, 1990). Mishel (1990) argues that uncertainty is a cognitive state, whereas vigilance, as seen in the Hospital High Vigilance theory, is derived more from an emotional response. This could be attributed to the origins of the UIT and RUIT, which are influenced by a cognitive psychologist (Budner 1962, Shalit 1977, Bower 1978, Lazarus 1974).

Vigilance as being used in the substantive theory presented in this study to recognise uncertainty can reduce ambiguity and increase understanding of the informal carers' world. However, the relationship between control, vigilance, and uncertainty needs further investigation, and outside the scope of this study. Meanwhile, the Hospital High Vigilance Theory could explain the source of the individual uncertainty, which can help the healthcare professionals and informal carers plan for, effectively manage or reduce their uncertainty and thus the high vigilance state.

6.3.3 Hospital High Vigilance theory and self-transcendence

The priority of the healthcare workers should be to understand and facilitate patients and their relatives' capacity for well-being in the context of complex health-related experiences (Reed 2018). The Hospital High Vigilance theory shows how admission and hospitalisation of a patient with CHF is a difficult and highly stressful experience for the informal carers and therefore experienced an adversity. This was reflected in the social process represented in the theory. Therefore, the Hospital High Vigilance theory will be compared with the theory of self-transcendence developed by Reed (1991) and Maslow's hierarchy of needs (Maslow 1954). Self-transcendence involves 'understanding how people transcend adversity and the relationship among psychosocial development, mental health and well-being' (Reed 2018, p. 119). Therefore, it is necessary to explore how this substantive theory compliments and/or differs from the concept of self-transcendence.

Reed (1991) developed the theory of self-transcendence on two major assumptions. The first is that the people are integral with their environment and the connections with self, others, and the environment (Reed 1991, 2018). The second assumption is that self-transcendence is a human resource that demands expression, that is part of the human being, and that facilitates the potential for well-being (Reed 1991, 2018). The Hospital High Vigilance theory through symbiotic interactionism examined the relationship/interactions of the informal carers between self (loss of dignity, duality, duty, invisibility, and vulnerability), others (symbiotic relationship) and the environment (difficulties in gaining access and disempowerment). The expression of these interactions with self, other and the environment in the substantive theory presented in this study was conceptualised as a high vigilance state which can be derived from a possible fear of loss (death) of the informal carer's relatives and the loss of control of their relatives' care. The theory of self-transcendence is based on three major concepts: self-transcendence (the capacity to expand personal boundaries), well-being (a sense of feeling whole and healthy) and vulnerability (awareness of mortality or risk to one's well-being). The Hospital High Vigilance theory could be compared to the self-transcendence in a temporal way in which informal carers examined their past experiences to be able to connect and give meaning to what was happening during the admission and hospitalisation. These meanings from

the past experiences increased the sense of high vigilance state. This could be explained because the informal carers recognised the awareness of their vulnerability in the face of their relatives' instability and mortality. Moreover, the sense of well-being and of feeling whole was threatened during the admission and hospitalisation. This was reflected by the notion of a break in the symbiotic relationship and striving towards resilience, indicating an unhealthy state of being. In other words, high vigilance in the substantive theory shows a negative indicator of well-being, which is affected by the vulnerability of the informal carers through past experiences and affects the ability of growth and development (self-transcendence) of the informal carers. Reed (2018) argues that self-transcendence could mediate the effects of vulnerability on well-being. Without self-transcendence, vulnerability could diminish rather than sustain the person's well-being.

Therefore, the Hospital High Vigilance theory could give the healthcare professionals tools to understand and facilitate well-being in situations of increased vulnerability. This could be done by devising medical and nursing interventions that support the informal carer's inner self-transcendence by reducing the vulnerability of the informal carers and thus increasing their well-being. Therefore, this could help the informal carers cope or be resilient in an adverse situation such as a sudden worsening and instability of a patient with CHF (resiliency will be discussed in Section 6.3.7.)

Another meaning for the concept of self-transcendence was given by Maslow's Hierarchy of Needs (1954). The meaning of transcendence, in the updated Maslow theory, is the ability to focus beyond the personal self and show characteristics like altruism, spiritual awakening, and liberation from egocentricity (Maslow 1996). However, Maslow's theory is about motivation, which suggests that five categories need to influence an individual's behaviour: physiological, safety, love and belonging, esteem, and self-actualisation (Maslow 1954). A person must address and achieve the basic physiological and safety needs in order to move on to the next level of fulfilment (Maslow 1954). Therefore, self-transcendence is based on achieving all these needs before being altruistic and liberating oneself from egocentricity (Maslow 1996).

Various literature adapted Maslow's Hierarchy of Needs in multiple areas of healthcare. A study conducted by Zalenski and Raspa (2006) in hospice and palliative care concluded that apart from their basic needs, patients highly valued the belonging and affection from their relationship with the family, which helped them self-actualise and thus reach self-transcendence at the end stage of their life. This was corroborated in the Hospital High Vigilance theory, whereas participants (patients) valued the presence of their husband, wife, or daughter (informal carers) near them during admission and hospitalisation. However, admission and hospitalisation threatened these needs because, as seen in the Hospital High Vigilance theory, participants (informal carers) ignored their basic needs (such as not eating, not sleeping, staying near the patient for long hours). After all, the informal carers felt that their relatives were unsafe (harm avoidance). This was due to the patient's instability; fear of death and the hospital norms and routines threatened the intimate relationship between informal carers and patients. This conforms to Weisense, Kjervik and Anderson's (1992) study which found that the informal carers' need for belonging and affection affected their level of safety and security and thus their physiological needs.

Moreover, in the Hospital High Vigilance theory, the admission and hospitalisation impacted the informal carers' sense of belonging, love needs, and esteem needs (self-blaming). Consequently, the informal carers' self-fulfilment needs were not addressed, resulting in emotional turmoil and, thus, a high vigilant state. This confirms and corroborates Maslow's hierarchy of needs theory (1954). Humans must satisfy their basic needs (esteem, belongingness, love, safety and physiological) before they can attend to or achieve self-transcendence. In the Hospital High Vigilance theory, admission and hospitalisation impacted and deprived the informal carers (and sometimes even the patients) of their basic needs and motivated them to fulfil such needs (by being in a state of vigilance to enhance safety, belongingness and love needs). This corroborated the mixed-method case study conducted by Stirling et al. (2014) with fifty informal carers using adult day respite services. Based on Maslow's hierarchy of needs, the informal carers valued the need to provide physiological care and safety to the patients to achieve a higher level of belongingness, love, and esteem (Stirling et al. 2014).

During hospitalisation, the informal carers ignored their basic and psychological needs to care for their relatives. This could result in the informal carers will not be able to take care of their relatives after discharge due to disempowerment and thus increasing the risk of institutionalisation (Scholzel-Dorenbos et al. 2010). Therefore, healthcare professionals should address the emotional, physical and safety needs of the informal carers within the hospital environment to give the informal carer the tools to take care of their relatives even when admitted. With the help and application of Maslow's theory (1954), the Hospital High Vigilance theory could help the healthcare professionals adopt a holistic approach to taking care of the patient and the informal carer in the hospital environment. If the Hospital High Vigilance theory is applied together with Maslow's hierarchy of needs theory (1954), it could identify the informal carers' physical, emotional, social, and intellectual needs and how the hospital environment could impact the informal carers' ability to take care of their relatives and their reaction.

However, one must use the Maslow theory (1954) with caution, as research contests that the needs are fulfilled in a hierarchal method as predicted by Maslow's model (Hagerty 1999, Rauschenberger et al. 1980, Wicker et al. 1993). In a study of human needs across cultures conducted by Tay and Diener (2011), data from over 60,865 participants in 123 countries was collected to assess six needs similar to Maslow's, and tests were conducted to see if the needs were fulfilled in the order predicted by Maslow's hierarchy of needs model (1954). They found that the needs were essentially universal but that the fulfilment of one need was not dependent on the fulfilment of another (Tay and Diener 2011). Moreover, the study also showed that when most citizens in a society have their basic needs met, more people focus on pursuing a fulfilling and meaningful life (Tay and Diener 2011). Taken together, the results of this study suggest that self-transcendence can be attained before all of the four other needs are met, but that having one's most basic needs met makes self-transcendence much more likely. Therefore, as seen in the Hospital High Vigilance theory, during admission and hospitalisation, the informal carers' most essential needs were the safety of their relatives suffering from CHF. This is important to sustain their love and belonging through a symbiotic relationship to fulfil and move to other needs, thus ignoring their own basic physiological needs. This was evident in this study as the informal carers increased their vigilance and ignored themselves and their basic needs to

be near and protect their relatives (advocacy). The Hospital High Vigilance theory highlighted that the informal carers shifted the focus from the self to their relatives by being hyper-vigilant. This could be a sign that the informal carers are ignoring their needs and consider the needs of their relatives more important than their needs and could be a sign of self-transcendence. Furthermore, the substantive theory highlights how informal carers are motivated intrinsically rather than extrinsically. This is because the central concept of Hospital High Vigilance highlighted the notion of presence, caring and watchful waiting to avoid harm to their relatives while hospitalised. The sense of duty and caring stressed in the substantive theory emphasises an intensive focus from the informal carers on doing what is suitable for their relatives. Finally, the intense emotional turmoil expressed by the participants was triggered by the shift in focus, shift in values and an increase in moral concern. These characteristics, shown in the Hospital High Vigilance theory, could be attributed to a person with a self-transcendence personality (Reed 2018).

However, another explanation could be that the satisfaction of fundamental needs, such as physiological and safety needs, takes precedence over a high-level pursuit such as personal growth, but not in a hierarchal way (Maslow 1943). Informal carers in this study identified themselves with their relatives, thus ignoring their interests (basic needs) and investing more in the safety of maintaining their symbiotic relationship during hospitalisation. However, due to this long-standing symbiotic relationship, the safety of their relationship had always been met. Therefore there was an increase in tolerance for a short period if a need was not met or deprived (when hospitalised) (Maslow 1943). This was described by Maslow as a type of self-transcendence in which people who have had their basic needs satisfied throughout their life (safety in the long-standing relationship) can cope and motivate (hypervigilance) themselves more to fulfil the need of their relatives in a period of crisis (like hospitalisation). This was further corroborated by Scholzel-Dorenbos et al.'s (2010) study conducted on patients with dementia and their respective informal carers.

However, unmet needs have to be addressed. As seen in the Hospital High Vigilance theory, the unmet need for safety exacerbated anxiety and stress (also seen in Scholzel-Dorenbos et al. 2010). The Hospital High Vigilance theory could help the healthcare professional evaluate the needs of the informal carers during

admission and hospitalisation and thus holistically address them and treat the patient and informal carers as dyads instead of as an individual. Furthermore, an increased understanding of the specific needs of the caregivers may lead to the development of interventions that positively impact caregiver well-being (Kobiske and Bekhet 2018). This was confirmed by Wilkinson and McAndrew (2008) in recognised the need of the informal carers to be recognised and valued. The fourth level of Maslow's hierarchy is self-esteem needs; therefore, people need to engage psychosocially to gain recognition and have a sense of contribution to feel accepted and self-valued. Imbalances at this level can result in low self-esteem (Wilkinson and McAndrew 2008), which is shown in the disempowerment, loss of dignity, vulnerability, and invisibility component of the substantive theory, resulting in high vigilance.

6.3.4 The symbiotic relationship in Hospital High Vigilance theory

The above two sections showed how the concepts of uncertainty and self-transcendence compared to the Hospital High Vigilance theory and affected the individual's reaction (informal carers) in a situation like admission and hospitalisation of their relatives. However, as was hinted in the above sections, another reason could have affected the high vigilant state in the theory. This could be the kind of relationship that exists between the informal carers and the patients. It is represented as a symbiotic relationship in theory, which means that both the informal carer and patient identify themselves as one being that benefits from each other based on intimate interaction on a long-term basis. This relationship was built over the years and means that the relationship of the informal carers with their relatives evolved during the years and was fluid according to the needs of the individual. The above can be described as a normal relationship in which two people interact and behave towards each other through connection, blood or marriage. However, this relationship was based on a delicate balance between informal carers and their relatives, which was affected by sudden hospitalisation and admission.

The term symbiotic relationship was conceptualised in the literature in various ways, which is interesting to examine in conjunction with the Hospital High Vigilance theory. The similarity was seen in the health literature concerning the relationship between the informal carers and their relatives in this study, although in a different connotation. The relationship between two older adults' dyads was

described as a symbiotic caregiving role, e.g., one was responsible for physical caregiving tasks while the other assumed more cognitive or decisional duties (Happ 2013). Similarly, data in this study suggests that most informal carers and their relatives rely on each other for basic physical, cognitive, or decisional tasks such as cooking, cleaning, paying the bills, booking an appointment, and many more (see Section 5.4.1). For this reason, the relationship of informal carers and their relatives suffering from CHF was conceptualised as symbiotic.

Similarly, Azevedo and Santos (2006) described the relationship between physically disabled persons with spinal cord injury by trauma and their respective caregivers and family members as a symbiosis of disability with the patient – to live for their physically disabled family member. On the other hand, Rask et al. (2003) found that symbiosis was significant to emotional closeness and bonding and clearly defined identities. This is even evident in the Hospital High Vigilance theory. Participants were constantly examining themselves within the context of their relationship, which is based on intimate interaction, companionship, and trust. However, what is different from Rask et al. (2003) is that while the authors discussed clearly defined identities (the son, daughter, father, or mother), the new substantive theory emerging from this study suggests that the informal carers and their relatives are not independent identities. The participants of this PhD study were forming and reforming themselves within each unique relational context within their relationship together which has one specific identity and thus why it was conceptualised as symbiotic.

Premberg et al. (2008) conducted a phenomenological study on ten men 12–14 months after becoming fathers. The participants supported their wives in the symbiotic relationship that exists between the mother and the child. Similarly, the Hospital High Vigilance theory conceptualised the symbiotic relationship as based on support and acceptance at home. However, the difference is that the participants' relationship with this study somewhat evolved and changed during admission and hospitalisation. This conforms to Ellis et al (2015) statement that a family is a symbiotic unit, and health-related conditions affect the family unit.

Yet, many similarities were found between the concept of the symbiotic relationship within the Hospital High Vigilance theory and concepts concerning family caregivers taking care of relatives with chronic illnesses. Family caregivers

often love the person they choose to care for, are in a marriage or partnership with that individual, or have a symbiotic attachment to the care recipient that inspires them to provide necessary help for what is frequently an indeterminate and prolonged period of time (Gibbons et al 2014). The meanings of a relationship for a female spouse taking care of her partner who suffers from a stroke post-discharge was described as melded together in a symbiotic way (Backstrom and Sundin 2007, Backstrom, Asplud and Sundin 2010). This is similar to what the study participants discussed during the interviews where frequently identified themselves as being one. Furthermore, the relationship between family members suffering from chronic pains was described as an intense mutual involvement (Smith and Friedemann 1999). Informal carers visualise their ideal family as a group of individuals with symbiotic relationships, intense identification with the family system and much likeness with little individuality (Smith and Friedemann 1999). These concepts could further justify the reaction of hypervigilance in theory. The informal carers in this study value their relationships with their relatives suffering from CHF.

The Hospital High Vigilance theory described how the relationship between the informal carers and their relatives (patients) evolved during the years. Some informal carers even stopped working or completely changed their lifestyle to support their relatives suffering from CHF. The similarity to the substantive theory was seen in the literature concerning parents and their children. Cipolletta et al. (2015) showed that when a child becomes chronically ill, the child becomes the centre of the mother's life, who usually stops working and creates a stronger symbiotic link with the child, devoting her life to the child's care, especially during an illness. Similarly, Darmi et al. (2017) stated that the relationship between the parents and the child changed from a special relationship (before diagnosis) to a frightening 'stranger' (period of diagnosis) to a symbiotic bond (period of remission). In their attempt to prevent a relapse, the parents tried to function on behalf of their nonfictional son or daughter, which led to the formation of a symbiotic relationship over time.

Wang et al. (2017) examined the relationship between carer and patient extensively and identified and conceptualised it as symbiotic. Progressive compensatory symbiosis was identified as the main category, with three other components: awareness of unbalanced intimacy, commitment, and

implementation of a compensatory scheme. Similarly, to the Hospital High Vigilance theory, Wang et al. (2017) identified the relationships between informal carers and their relatives suffering a chronic disease as symbiotic. Wang et al. (2017) suggested that the caregivers' relationship became increasingly symbiotic, which was the case in the Hospital High Vigilance Theory. The participants in this study had known each other for a long time. Taking care of the chronic illness was not initiated when there was an admission and hospitalisation of the patient. The main difference was that Wang et al. (2017) described the symbiotic relationship's build-up and progression during the chronic life trajectory, while the participants of this study described this relationship as an already established one. However, what is missing in the above literature, which the Hospital High Vigilance theory adds, is how this symbiotic relationship mutates, changes, or evolves during an admission and hospital setting or in a crisis. As stated in the above literature, the symbiotic relationship between informal carers and their relatives can be expected and described as a normal consequence in a chronic illness trajectory.

6.3.5 Hospital High Vigilance theory and transition theories

A possible explanation of how the relationship between the informal carer and their relatives evolved and changed during admission and hospitalisation could be given by looking at the transition theories literature. The Hospital High Vigilance theory describes how a sudden admission to the hospital is an abrupt interruption of the informal carers' and relatives' lifestyle or routine. However, the informal carers continued to take care of the patient in one way or another during hospitalisation. The Hospital High Vigilance theory helps to explain that informal carers do not stop their duty of care for their relatives but try to adapt or to 'transition' in the hospital environment to continue to take care of their relatives, and regain control over the care of their relatives and over their relationship. Understanding this adaptation or transition is important because in the Hospital High Vigilance theory, the healthcare professionals took over the care from the informal carers as seen in the gaining access (difficulties) and disempowerment component of the Hospital High Vigilance theory. The informal carers still strived towards resilience, e.g., the informal carers did their utmost to be near the patient to take care of and protect their relatives, which resulted in a high vigilant state. The Hospital High Vigilance theory could be compared to a

transition because a transition was defined as an alteration of roles, relationships, routines, and assumptions (Schlossberg 1981, 2011). In the Hospital High Vigilance theory, an admission altered the informal carers' roles (disempowerment, duality), relationships between the informal carer and patient (symbiotic relationship), routines (a break-in-life trajectory) and assumptions about self and life (the patient is going to die or get worse, or the informal carers are not taking care of their relatives adequately).

Moreover, any transition is complex, changing fundamental life patterns and vulnerability (Im 2018). This was evident in the substantive theory presented in this study, which highlighted the complexity of the sudden onset and exacerbation and instability of the patients' conditions in which a break-in-life trajectory occurred. This underlined the vulnerability of the informal carers in this situation and thus evoked a high vigilant state. Therefore, the Hospital High Vigilance theory gives a vital meaning and understanding of what is happening to the informal carers during the admission and hospitalisation phase, significantly how the relationship between the informal carers and their relatives evolved and/or changed. Adapting the Hospital High Vigilance theory could provide a structure for the healthcare professionals to analyse the situation adequately (Schlossberg 1981, 2011). This is because applying the Hospital High Vigilance theory and a transition theory could help healthcare professionals strengthen their resources by understanding the admission/hospitalisation phase from the informal carer's point of view.

Schlossberg (1981, 2011) defined a transition as any event or non-event that results in changed relationships, routines, assumptions, and roles. Schlossberg's transition theory has four main factors that influence a person's ability to cope with a transition: situation, self, support, and strategies (Schlossberg 1981, 2011). Comparing these four categories for coping in Schlossberg's transition theory (1981, 2011) to the meaning of informal carers in the Hospital High Vigilance Theory, similarity was seen between the two. Furthermore, Hospital High Vigilance Theory adds new knowledge by identifying the situations and resources that informal carers experience/need during admission and hospitalisation.

The situation factor described by Schlossberg (1981, 2011) refers to the persons' situation at the time of the transition. Similarly, the Hospital High Vigilance theory

explained that the factor was the acuteness and acceleration of the chronic illness of the patient, which, although somewhat expected by the informal carers, was still considered a one-off event in terms of the participants' lifestyle/normality, thus the sudden admission caused a break-in-life trajectory. Controlling the situation during transition is seen as one of the major coping factors by Schlossberg (1981, 2011). However, in the Hospital High Vigilance theory, the informal carers tried to take control of their relative's care during hospitalisation by spending longer hours near their relatives during hospitalisation, phoning their relatives and the ward staff, or making a rota system between their siblings to ensure that their relatives were not on their own and thus these actions increased their vigilant state. The informal carers had no control over other aspects of hospitalisation like visiting times, staff perceptions and attitudes, and acuteness and instability of their relatives' condition. In this study, for the informal carers, control was regained when their relatives were discharged home, and thus their status quo was regained. A role change resulting from any form of transition is a significant source of stress during this situation, as stated by Schlossberg's Transition theory (1981, 2011). In fact, in this study, an informal carers' role change was noted when the patient was admitted to the hospital. The informal carers went from being the main carers of their relatives to being spectators to the care given by the healthcare professionals, as explained by unmet needs, vulnerability, loss of dignity, loss of control, duality and disempowerment, all perceived as a loss by the informal carers. Furthermore, the duration of this transition was another factor that affected coping mechanisms during a transition (Schlossberg 1981, 2011). The informal carers in the Hospital High Vigilance theory saw the duration of this transition as temporary. However, uncertainty characterised it (fear of death or getting worse), resulting in hypervigilance. Schlossberg's Transition theory explains that previous experience with similar transitions could help the person adapt and cope more easily (Schlossberg 1981, 2011). Similarly, the past experiences component of the Hospital High Vigilance theory explains that most of the informal carers had multiple admissions, bad past experiences, took care of other relatives, or were healthcare professionals. However, the informal carers still found difficulties in coping and reacted in a high-vigilance way, which is explained by Schlossberg's Transition theory (1981, 2011) as concurrent stress at that moment affecting the coping of a transition. Similarly, in the duality component of the Hospital High Vigilance theory, the informal carers clearly

explained that they had other responsibilities and roles in their lives, and hospitalisation made it hard to abide by different roles. Some participants ignored their other roles to be vigilant during the hospitalisation of their relatives.

The next component in the Schlossberg Transition theory (1981, 2011) was the self-factor, which referred to the person's inner strength for coping with the given situation. Past experiences, gender, age, and background were significant self-factor components in coping with the transition (Schlossberg 1981, 2011). Although the past experiences (intuitive knowledge) component of the hospital vigilance theory states that because of their past experiences participants increased their level of awareness and vigilance, there seemed no apparent difference in the reaction to the hospitalisation when taking into consideration the participants' gender, age, and social background. However, unmet needs, values and commitment were observed by the participants, which increased the self-factor component of the participants.

Another factor for coping during transition described by Schlossberg (1981, 2011) was support, which was critical to one's sense of well-being. Similarly, the participants in the Hospital High Vigilance theory had a symbiotic relationship and good support from other family members and a network of friends that helped them during this period. However, informal carers felt less support than expected from the institutions and healthcare professionals. This resulted in a high level of vigilance by the informal carers in this study.

The last component of the Schlossberg Transition theory (1981, 2011) were strategies for coping during a transition. Similarly, during admission and hospitalisation, the informal carers in Hospital High Vigilance tried to modify the situation (as described in striving towards resilience component), and control the meaning of the problem (as defined in striving towards status quo component). However, although the informal carers tried to modify or change the admission by delaying it, they could not avoid it because of the acute exacerbation of symptoms by the patient. Therefore, the participants attempted to reframe the situation in their meaning. However, the informal carers did not need aid in managing the stress after discharge from the hospital. Going back home and regaining control of the situation by continuing their routine and lifestyle was more important and less stressful.

Role changes in a planned transition can be controlled and predicted; thus, they can be assessed without a great degree of difficulty (Schlossberg 1981, 2011). However, in the case of sudden admission of a patient with heart failure, role changes of the informal carer are unpredictable. The Schlossberg's Transition theory (1981, 2011) is helpful to identify the needs of the informal carers during admission and hospitalisation of their relatives suffering from CHF. However, it does not explain what is really happening in the social process of admission and hospitalisation. Besides that, the informal carers did not want to change their lifestyle and did not perceive or want change but wanted to go back to their life trajectory and their symbiotic relationship. However, by applying a theory like Schlossberg's Transition theory (1981, 2011), a more in-depth explanation could be given to the social process of the informal carers during admission and hospitalisation of their relative suffering from CHF, as explained above.

The suitability for using Schlossberg's Transition theory to compare the informal carers' experiences during admission and hospitalisation was illustrated in her seminal articles where she discussed the development of the model in which transitions of all kinds can be analysed and possible interventions formulated (Schlossberg 1981, 2011). Schlossberg's Transition theory (1981, 2011) was used extensively in educational and counselling settings. In the nursing sphere, it was used in nursing education of qualified nurses undergoing further nursing studies (Wall et al. 2018, Buckingham Poronsky 2013, Dela Cruz 2013). However, no articles or literature directly connected this type of transition to informal carers, especially during admission and hospitalisation. Schlossberg (1981, 2011) stated that it is not the transition per se that is critical, but how much it alters one's roles, relationships, routines, and assumptions. Therefore, Hospital High Vigilance theory states how the informal carer's role, relationship, routines, and assumptions were altered, sometimes to the core.

The main difference between Schlossberg's Transition theory and the Hospital High Vigilance theory is that transition takes time, according to Schlossberg (1981, 2011). In contrast, time was limited due to the sudden onset and limited hospital stay in hospital vigilance theory. However, the informal carers' reaction in the Hospital High Vigilance theory was similar to what Schlossberg (1981, 2011) explained in her theory. First, the informal carers think of nothing but their new role, relationship, and routines in the hospital to protect, care for and help

their relatives. However, the informal carers in this study did not separate from their past but moved towards their new role (while their relative was hospitalised) as defined in Schlossberg's Transition theory (Schlossberg 1981, 2011). They embraced the past and the present and did not see any future because of the instability of their relatives while they were in the hospital. The informal carers strove towards resilience during hospitalisation; they wanted to go back to their normal routine and embrace their previous life at home (striving towards the status quo). Schlossberg's Transition theory (1981, 2011) moves towards change, growth, and embracing the future, which is different from the Hospital High Vigilance theory, which focuses more on stability and regaining normality, thus establishing the symbiotic relationship between the informal carers and their relatives.

However, the Schlossberg Transition theory (1981, 2011) can be applied to various situations and realities. One major criticism is that this theory focuses excessively on the transition phase and neglects what happens after the transition occurs. Furthermore, Schlossberg's Transition theory (1981, 2011) states that every transition brings change, and does not challenge the fact that people (such as the participants in this study) prefer to stay in a status quo; this is because every change in the patient's status could be seen a further step to death of their relatives and a break in the informal carers' and their relatives' symbiotic relationship. Schlossberg's Transition theory (1981, 2011) applies to planned transitions like becoming a parent, going back to school, and switching carers. Furthermore, Schlossberg (1981, 2011) stated that the transition exists if the participants perceive a transition. Although most of the Hospital High Vigilance theory components can be compared, conceptualised, and explained in the context of Schlossberg's (1981, 2011) transition theory, no participant in the current study mentioned a transition or gave the meaning of a transitional phase during admission and hospitalisation. It may be because hospitalisation is for a short period, and the informal carers push to go back to their status quo/back to normality rather than seeing their relative die or get worse.

The Hospital High Vigilance theory evolves around the social process of informal carers during admission and hospitalisation of their relatives suffering from CHF. Informal carers play a major role in supporting patients during critical transitions (admission, hospitalisation, and discharge) (Naylor and Keating 2008). The

Hospital High Vigilance theory explained the social process involved in these critical transitions from the informal carers' and patients' point of view. The transitional care model (TCM) developed by Naylor et al. in 1994 is widely used in these types of transitions. TCM involves and addresses the gaps in care transition by including a broad range of services to promote safe and timely passage of patients between levels of healthcare and across different care settings (Naylor and Keating 2008). It addresses the patients' chronic care needs across time, including identifying patient-specific concerns, medication adherence and persistence, assessing and supporting health knowledge, and utilising remote patient monitoring (Grover and Joshi 2015). However, the TCM focuses mainly on the patients' needs, and caregivers are recommended to be included in the care (Naylor and Keating 2008). Literature highlights significant gaps in care for informal carers taking care of their relatives during these transitions, leading to adverse events, unmet needs, low satisfaction with care, and high rehospitalisation (Naylor and Keating 2008). The TCM and other models focus on the patients' process and outcome, and the informal carers' distinct role should be recognised and acknowledged more to help the patient (Naylor and Keating 2008). The Hospital High Vigilance theory aimed to address this gap by highlighting the informal carers' social process during the transition of admission, hospitalisation, and discharge.

6.3.6 Hospital High Vigilance theory and status quo

This section will focus on how the terms status quo and striving towards status quo were used in the Hospital High Vigilance theory, and compare this to the available literature. Status quo in Hospital High Vigilance theory refers to the state of normality of the informal carers, of staying at home to take care of their relatives rather than going to the hospital due to an acute episode of exacerbations of CHF. This results in a delay in the decision-making of the informal carers to go to the hospital.

There are myriad reasons why an informal carer might delay an admission or seeking help, including religious beliefs, informational gaps, specific patient requests and lack of trust in healthcare (Anderson 2003). In the current study, however, the main reason for this delay seems to be a cognitive bias. Cognitive bias means that the informal carers created their subjective reality about the sudden onset of chronic illness. The Hospital High Vigilance theory tried to

understand the informal carers' cognitive bias during admission. Understanding the role of cognitive biases in the status quo context might help the informal carers and healthcare professionals improve the communication between the healthcare professionals and the informal carers when these internal conflicts occur. The status quo bias term is mainly used in psychology. Little was found that connects the term status quo bias in healthcare, especially with the informal carers taking decisions when their relatives need to go to a hospital for acute care. A rational choice would be that the informal carer, during exacerbation of their relatives' chronic symptoms, will immediately seek the help of the hospital and get their relatives to acute care immediately. However, this rational choice was not always taken, and the informal carers decided not to seek immediate help when their relatives exhibited acute symptoms of their chronic illness. This was inconsistent with a rational choice of seeking immediate help and was therefore considered irrational. The status quo bias affected the decision-making preference for the current state of affairs, and resulted in a lack of changing their behaviour in order to seek help as soon as an exacerbation of chronic illness manifested. Most of the people are psychologically uncomfortable with change and will stick with the current state of affairs, even when it directly conflicts with their preferences (as seen in this study) (Anderson 2003). Another reason could be that the informal carers fear a negative outcome because of the hospitalisation, i.e., dying or getting complications.

However, a bias could be present when there is a repetition of a situation and a situation occurring even despite changing the situation (Anderson 2003). The above could be explained as decision-delaying that led to trying to maintain the status quo and delaying seeking help, which could be seen as unjustified given the alternative of seeking advanced and specialised care for their relatives in this critical situation. Yet informal carers and even the patients continued seeking the default no-action, delaying or no-change options. This corroborates Anderson's (2003) literature review of the psychology of doing nothing. Although Anderson's (2003) literature review was not conducted on informal carers or in a health sector setting, it could give a possible explanation of the actions of the informal carer. The informal carers of this study could have been influenced by a rational and emotional phenomenon that affected the decision-making process during the sudden onset of acute symptoms and thus having to go to the hospital. Feelings

and emotions like anticipated regret/blame (fear of dying or getting worse) and selection difficulty (going against their relatives' wish) favoured the status quo bias and thus delayed the seeking of help (Anderson 2003). However, this decision avoidance or preference for maintaining the status quo resulted in regret by the informal carers in the Hospital High Vigilance theory, when they recognised that their relatives could have died by their delay. Emotions form an integral part of the Hospital High Vigilance theory, as informal carers are sometimes guided by these emotions and act according to their feelings, resulting in a higher vigilance state. This corroborated the rational-emotional model of decision avoidance described by Anderson (2003), where emotions play an essential part in the decision-making process and status quo bias. Anderson (2003) continued to argue that the effects of these emotions in decision-making could not be viewed in isolation but are connected to other factors that might affect decision-making. Hospital High Vigilance theory identifies these factors concerning the informal carers during admission and hospitalisation as the symbiotic relationship, striving towards status quo and striving towards resilience.

However, research provides abundant evidence for such a status quo bias, further explaining the informal carer's decision to prefer the status quo. Ritrov and Baron (1990), in their work about reluctance to get vaccinated, explained the omission bias and ambiguity as the main reason for participants' decision-making reluctance to vaccinate. Baron and Ritrov (2004) further expand on this and identify individual differences and normality to explain why status quo bias happens. In comparison, withholding treatment identified conflict within the family as the main reason for the status quo (Breen et al. 2001). Fear of negative impact is the main reason for the doctors not to change their status quo (Bonnen et al. 2011). Fear of doing harm or getting worse prevented the participants from changing their behaviour, thus preferring the status quo (Nicolle et al. 2011). Anticipated regret before making a decision could also affect the participants in maintaining the status quo (Mannetti et al. 2007), whereas Leonhard, Keller and Pechmann (2011) explore the uncertainty in a situation that affects decision-making, leading to a preference for the status quo. Patients and informal carers chose to stick with what treatment they already knew rather than change to a new treatment (Halpern et al. 2015). The above literature mirrored and reflected the informal carer's choice and reasoning, explaining why informal carers preferred

to maintain or go back to the status quo in the Hospital High Vigilance theory. Other factors were examined in the Hospital High Vigilance theory that affected the informal carers during admission and hospitalisation, mainly the relationship between the informal carers (discussed in Section 6.3.5.) and the patient and striving for resilience (discussed in Section 6.3.7) that participants experienced during hospitalisation.

6.3.7 Hospital High Vigilance theory and resiliency

This section will discuss the participants' co-construction of Hospital High Vigilance theory and literature surrounding resiliency. As discussed in the above sections, the Hospital High Vigilance theory is about the reaction of an adverse situation as sudden hospitalisation of a relative suffering from an exacerbation of CHF illness. The theory highlighted the vulnerability of the informal carers in that situation who then reacted in a high-vigilance way. This reaction was described as a means of coping by the informal carers and was conceptualised as striving towards resilience instead of being resilient. Striving towards resilience in the Hospital High Vigilance theory means that the informal carers during admission and hospitalisation of their relatives are trying hard to bounce back, cope, adjust or adapt to the sudden admission; thus, a break in the symbiotic relationship was observed. Therefore, the informal carers were experiencing difficulties during hospitalisation to be resilient, which were conceptualised as a break in normal resilience and striving towards resilience. Consequently, striving towards resilience elevated the informal carers' guard and watch or vigil over the patient to avoid harming their relative.

Resilience was used as a concept in various disciplines with different properties and characteristics. In social sciences, resilience is about the positive factors or individual strength that contribute to healthy development and positive outcome (Fletcher and Sarker 2013, Windle 2011). The behavioural science experts concluded that the definition of resilience is determined by the context of the study (Southwick et al. 2014). The common denominator in all areas is achieving or bouncing back from an adverse experience (Earvolino-Ramirez 2007). The above information highlights the variety of definitions that exists in the literature about resilience. Therefore, a clearer operational definition of resilience in the context of Hospital High Vigilance theory is needed, which will be discussed below.

The Hospital High Vigilance theory highlights the consequences of a sudden worsening of chronic illness, and consequently the admission and the hospitalisation of the relatives, on the informal carers. Thus, the Hospital High Vigilance theory was co-constructed to focus on the risk factors that prevented resilience rather than examining the positive factors or individual strengths that contribute to healthy development and positive outcomes as often described in social sciences research (Fletcher and Sarker 2013, Windle 2011). However, resilience should not be viewed as a static state but as a dynamic one. The Hospital High Vigilance theory described it as a process that affected both the symbiotic relationship and the outcome of vigilance. Therefore, this study does not explore resilience in general but what affected or prevented the informal carer from being resilient in a crisis situation of their relatives' condition and during admission and hospitalisation in hospital culture and norm context.

As seen in the Findings chapter, Section 5.5, resilience is related to stress; it can be conceptualised as a type of personality (i.e., hardiness) or through cognitive concepts of self-enhancement, repressive coping and expressing positivity (Bonanno 2004, Maddi 2005). The literature highlighted that resilience as a positive or successful adaptation, competence, and functioning during a stressful experience (Egeland et al 1993, Gaugler, Kane and Newcomer 2007, Kinsel 2005). Alternatively, resilience was conceptualised as a process encompassing positive adaptation within the context of significant adversity (Luthar et al. 2000, Richardson 2002). Bergman and Wallace's Multidimensional Model of Resilience (1999) included the individual (i.e., control, hardiness and self-concept) and family and community supports as the factors dealing with stress and coping ability. In contrast, Gaugler et al. (2007) explained two resilience profiles, low and high, concerning how caregivers use stress resistance to deal with caregiving burdens. Caregivers who perceive a low level of burden or stress when they have high levels of care demands such as instability and hospitalisation are deemed to have a high resilience (Gaugler et al. 2007). The informal carers in this study (as seen in Section 5.5) perceived mastery in care, self-efficacy, and internal locus of control when the patient was at home. Still, everything changed when the informal carer's relative required admission and hospitalisation. The importance of resilience for informal carers was highlighted by two articles published by Li et al. in 2018 and 2019. The family's higher resilience, the lower

stress and burden was on the caregiver (Li et al. 2018, 2019). Therefore, the Hospital High Vigilance theory attempted to understand better how resilience in an acute situation could contribute to understanding more the informal carers and thus could help the clinicians tailor interventions aimed to improve the well-being of the caregivers.

Another aspect of resilience was described by Carr's theory of Family Vigilance (Carr 2014) as the families care for themselves, persevering and maintaining their feeling of hope. Perseverance was demonstrated by the informal carers' will to carry on. Hope was captured in the informal carers' positive attitudes, and self-care was recognised as an essential element in maintaining perseverance and hope and, thus, overall resilience (Carr 2014). Similarly, the informal carers demonstrated perseverance in the Hospital High Vigilance theory. They carried on their duties, thereby maintaining a high level of vigilance but ignoring their basic needs and self-care. Therefore, there was a break in normal resilience, and striving towards resilience was seen.

On the other hand, Kobishe and Bekhet (2018) conducted a concept analysis of 11 articles to explore and understand resilience related to caregivers of a partner diagnosed with young-onset dementia. The authors defined resilience as a dynamic process that resulted in a positive adaptation after a diversity with flexibility, positive thinking, self-efficacy, resourcefulness, social support and spirituality. The above aspects of resilience described by Kobishe and Bekhet (2018) were found in the informal carers participating and co-constructing the Hospital High Vigilance theory. However, the informal carers in the Hospital High Vigilance theory did not bounce back, or were striving towards resilience during admission and hospitalisation. A higher vigilant state compensated for this by them watching over their relatives constantly. Moreover, Hospital High Vigilance theory adds the notion of disempowerment affecting the informal carers because of the hospital staff and hospital norms, and the informal carers' past experiences.

However, similarity was seen in literature that connects disempowerment with resilience in informal carers. Resilience was supported and affected by other family members, friends, hospital policies and healthcare professionals (Chen and Boore 2008). Powerlessness, feeling isolated, needing to be recognised and valued, and a desire for the partnership were identified as affecting resilience

(Wilkinson and McAndrew 2008). The above contributed to a lack of collaboration between the informal carers and hospital staff, which involved the ability to bounce back or resilience of the informal carers (Wilkinson and McAndrew 2008). Empowerment by individualised nursing interventions explicitly targeted to the family could help and develop family resilience and coping mechanisms (Foster et al. 2018). The above literature confirms that disempowerment with the notions of being submissive, imposing a routine and not being recognised identified by the participants in the Hospital High Vigilance theory affected the resilience of the informal carers during admission and hospitalisation.

The above literature failed to connect all the components of striving towards resilience and vigilance as presented in the Hospital High Vigilance theory. On the other hand, the connection between past experience and resilience as seen in the Hospital High Vigilance theory was seen in other literature. Resilience was affected by knowledge, experiences, and past personal experiences (Yeh and Chang 2012, Lima et al. 2019, O'Malley et al. 2016). Lack of knowledge or bad past personal experiences affected their current experiences, resulting in an increase in depression, anxiety, and lower resilience, and consequently their coping in their current situations (Yeh and Chang 2012, Lima et al. 2019, O'Malley et al. 2016). However, the connection and consequence of this lack of knowledge to a vigilant state are missing in the above literature. Moreover, the participants in the Hospital High Vigilance theory had a significant amount of knowledge, and some had good past experiences. However, they were still anxious and stressed and were still striving towards resilience, which resulted in vigilance. This adds to the originality and uniqueness of the Hospital High Vigilance theory.

Therefore, the Hospital High Vigilance theory could give a framework to the hospital staff to assess and assist the informal carers in helping them develop their resilience and coping capacity by providing interventions catering to the informal carers and not only the patient. Consequently, a better understanding of family resilience in an acute situation is necessary and can contribute to a better quality of life of the informal carers and thus help the hospital staff to tailor interventions aimed to improve the well-being of the informal carers (Mitchell et al. 2019, Ruckhold et al. 2019, Salminen-Tuomaala 2013, Wong et al. 2019).

6.4 Summary

This chapter began with a summary of the substantive theory before proceeding to evaluate how the components of the Hospital High Vigilance theory compared to the extant literature. Situating the various definitions of vigilance in literature and comparing the substantive theory with other pre-existing publications and theories confirmed the originality of the research. This analysis also tried to extend to some areas of already established literature or theories. Throughout this chapter, it was highlighted various significant contributions to knowledge which will be summarized in the next chapter. Reflections and implications for the relevance of this new initial substantive theory about informal care during admission and hospitalisation of a patient suffering with CHF will be discussed in the next chapter.

Chapter 7: Reflections and Implications

7.1 Introduction

This final chapter uses Charmaz's (2014) criteria for quality in a grounded theory to evaluate the new substantive theory. A reflection on potential future contributions of the new substantive theory, including implications for practice, management, education and future research, will follow. In addition, the limitation of the study will be acknowledged, with suggestions made for how to address these limitations in the future. This chapter will conclude with remarks that summarise the study's achievement concerning the initial aims.

7.2 Evaluation of the substantive theory

Evaluating a substantive theory depends on the research process that adopted the study in question—various methods and debates exist in evaluating these studies (Birks and Mills 2015). The primary discussion is the premise that research outcomes can be deemed accurate only if the produced research situation, methods, and process are rigidly controlled (Birks and Mills 2015). This implies that studies with a positivist position are more reliable and valid. It is reflected in the various hierarchy of evidence tables, whereas systematic reviews and randomized controlled trials are at the top of the hierarchy. Therefore, this could mean that qualitative research, like grounded theories, lacks rigour because of the lack of concrete procedural rules and predetermined processes and criteria (Goulding, 2002, Birks and Mills, 2015). This is because the tendency is that qualitative research is judged based on a one-way comparison with quantitative research (Sandewlowski 2008, Birks and Mills 2015). This should not be the case as quantitative and qualitative data are derived from two different paradigms and should be evaluated according to their respective paradigms (Sandewlowski 2008, Birks and Mills 2015). Therefore, the philosophical position must be clearly articulated and discussed, which will affect the methods and methodology and thus the quality and evaluation of the research (see chapters 3 and 4).

However, various methods and criteria exist in grounded theory to evaluate a research study. The most classic approaches to judging a grounded theory research are Glaser and Strauss (1967) - fit, understandable, general and control,

Glaser (1992) – fit, work, relevant modifiable, parsimony and scope, Corbin and Strauss (2008) – based on 10 basic criteria and 13 additional criteria and Charmaz (2014) – credibility, originality, resonance and usefulness. The above approaches were intended “to address the perceived lack of rigour in research aiming to generate theory” (Birks and Mills 2015 p.143). The above procedures depend on the premise of different philosophical positions of the other grounded theory schools. In Section 4.6, the methodological rigour of the research process integrated the components of trustworthiness in qualitative research (Lincoln and Guba 1985) with grounded theory procedural precision (Birks and Mills 2015). Table 9 will evaluate the substantive theory using Charmaz’s (2014) criteria for grounded theory (credibility, originality, resonance and usefulness). The researcher chose these criteria to ensure the evaluation of the substantive theory since this thesis used a constructivist approach. The below table is also mapped against the thesis chapters to show key evidence of meeting the criteria.

Table 9: Evaluation of the substantive theory

Criteria for a grounded theory	Criteria properties (Charmaz 2014) applied to the substantive theory and evidence of these properties in the thesis
Credibility	<ul style="list-style-type: none"> • The research achieved intimate familiarity with the setting or topic by having a consistent methodology and methods, and the process of conducting grounded theory research was rigorous – as explained in chapters 3 and 4. In chapter 1, section 1.3 - my personal and professional motivation showed my familiarity with the setting and topic before and during this research study. • Constant comparison methods occurred from systematically comparing between data and between categories – chapters 4 (section 4.4) and 5, appendices 3, 4, 5, 6, 7, 20. • There were solid and logical connections made between data generated, analysis and arguments defending the theory – Chapters 4, 5, 6 and 7.

- The amount of relevant data was adequate for theoretical sufficiency with transparency in how the theory emerged from the data and was not forced – Chapters 4 and 5, appendices 3, 4, 5, 6, 7, 20.
- The researcher's view and actions were presented through reflexivity, post comment interview sheet, journals and memoing throughout the research process – chapters 1 (section 1.3), 3 (section 3.3.3.3), 4 (Memos number 26112016 in section 4.2.1.2, 10082016 in section 4.2.1.2, 22112019 in section 4.4.2.3, sections 4.3.2, 4.3.3, 4.2.6.1, Figures 1, 2, 3, 4 and 5, tables 7 and 8) and appendices 3, 4, 5, 6, 7, 20
- There was enough detail in the presentation of data and analysis for thesis reader to form their own assessment of the concepts which emerged to construct the theory – chapters 4, 5 and 6, appendices 3, 4, 5, 6, 7, 20
- The data guided the inquiry process according to the participants' accounts during the interviews – chapters 4 and 5
- The actual participants' actual words were used in the final report – chapters 4 (section 4.3.5), 5 and appendices 3, 4, 5, 6, 7, 20
- The evolving theory was 'checked' by the participants through dyads interviewing and re-interviewing – sections 4.2.1.3, 4.3.4, and 4.6.2.2

Key evidence – methodological rigour through a detailed description of the research methods, sampling and recruitment process, inclusion and exclusion criteria, participants characteristics, scope, philosophical stances and methodology, memoing, reflexivity, theoretical sufficiency, peer review and feedback from tutors in the analysis process, apparent emergence of the central organising phenomenon

	and other major categories in the substantive theory – chapter 3, 4, 5 and 6, appendices 4, 5, 6, 7, 20.
Originality	<ul style="list-style-type: none"> • The categories were fresh, novel and offer unique insight into the care of informal carers during admission and hospitalisation of their relatives – Chapters 6. The central organising category of Hospital High Vigilance was not evident or found in the initial literature review represented in chapter 2. • The analysis provides a new conceptual rendering of the data - chapter 5 and 6 • The social and theoretical significance of the theory was explained – chapters 6 and 7 • The new substantive grounded theory challenged, refined and extended current concepts and other theories – chapter 6 <p>Key evidence- the topic was current and significant in addressing an established gap in the knowledge base (chapter 1 and 2); literature search in chapter 2 confirmed that a substantive theory about informal care of patients suffering CHF during admission and hospitalisation did not exist already, ways the theory made an original contribution to new knowledge were made clear (chapter 6 and 7)</p>
Resonance	<ul style="list-style-type: none"> • Meanings were co-constructed and made sense to the participants involved with the circumstances of the area. This was done during the interviews, using dyads interviewing (informal carers and patients) and re-interviewing some participants– sections 4.2.1.3, 4.3.4, and 4.6.2.2 • Links between concepts people and social process when the data indicate potential connections were made – chapter 4, 5 and 6

	<ul style="list-style-type: none"> • Analysis leading to the theory offered the informal carers deeper insights into their main concerns about the topic involved – chapter 5 and 6 <p>Key evidence – interview transcripts and memos, theoretical sampling, contemporary data collection and analysis, discussing the theory with thesis supervisors, colleagues, peers, dyads interviewing, re-interviewing, going back to the transcripts and confronting with personal experiences (chapters 4 and 5, appendices 3, 4, 5, 6, 7, 20)</p>
Usefulness	<ul style="list-style-type: none"> • The central organising phenomenon and major categories were abstract and generic with functional application across informal care – Chapters 5 and 6. • The new substantive theory offered practical interpretations of the data that informal carers and practitioners can use within their working practice – Chapter 5 and 6. • The theory provided practical insight for healthcare professionals to involving informal carers more in the care of their relatives during admission and hospitalisation – Chapters 6 and 7. • The theory can be tried out and tested in other substantive areas – Chapter 7. <p>Key evidence – memoing, peer review, reflections on the implications for the theory highlighted potential areas for the theory to be used and developed further – Chapters 4, 5, 6, 7 appendices 3, 4, 5, 6, 7, 20)</p>

7.2.1 Implications for management, clinical practice and education

A reflective appraisal of the potential use of the new substantial theory identified various implications for management and clinical practice. The concept of Hospital High Vigilance is built on the premise of a long-term relationship (symbiotic relationship) between the informal carer and their relative suffering from CHF. Sudden admission and hospitalisation, after a worsening of the CHF symptoms of the relatives, changed this relationship in terms of losing control of

the situation, disempowerment, difficulty in gaining access, unmet needs of the informal carers and loss of dignity. The findings of this study indicated that some hospital policies, protocols, and healthcare professionals' attitudes led to inappropriate behaviour and further stress to the informal carers. On these premises, the following implications for management, clinical practice, and education include:

- Protocols and policies could be changed to have more informal carer-oriented than professionals-oriented hospitals, e.g., more visiting time, and using more contact time with consultants by using technology such as tablets and cameras using video-call applications.
- The usage of healthcare professionals of the substantive theory could guide their clinical practice, in which they can reflexively evaluate whether involving, appreciating, and empowering the informal carers in their relatives' care should follow a set of standards or if the goal is better determined on an individual basis. This will ultimately aim to deliver care involving not just the patient but their informal carers too.
- Using the substantive theory in everyday clinical practice, the healthcare professionals need to know the type of relationship between the informal carers and their relatives. Being aware of this relationship does not mean the healthcare practitioner is willing or able to get involved too much in this relationship but could help the practitioners to identify the needs of the informal carers.
- Further explorations from the perspective of clinical practitioners, managers and educators could build on this thesis to develop other projects aimed at testing the theory within other clinical areas.
- Intensifying and extending the nursing students and qualified nurses training in communication, empowerment and involving the informal carers, especially in the hospital environment.

7.2.2 Implications for future research

This study has contributed to knowledge about the informal care of a patient suffering from CHF during admission and hospitalisation. However, this was essentially based on the informal carers' and patients' perceptions, actions, and interpretations of the social process involved. Future research is essential to

develop the substantive theory; on these premises, the following implications for the future researcher are being suggested:

- Research which includes the voice of the healthcare professionals. The substantive theory indicates that the informal carers' reaction was partly affected by the attitude of the healthcare professionals. It would be helpful to explore the healthcare professionals' perspectives, attitudes and awareness of the disempowerment component of the substantive theory.
- Research which includes other areas, e.g., other chronic diseases, long-term facilities, rehabilitation facilities, surgical conditions, palliative conditions, oncology conditions. This is important because this research was conducted in a specific context (patient suffering from CHF) and including other areas could enrich the substantive theory further.
- A deeper exploration of the association between symbiotic relationships and vigilance and the concept of vigilance and uncertainty. The participants value their relationship highly. It would be interesting to explore how this relationship between an informal carer and a patient suffering from CHF differs from other types of relationships. During the discussion, it was noted that the concepts of vigilance and uncertainty are connected. A deeper exploration would be fascinating in evaluating, contrasting and comparing the two concepts together.
- More research studies conducted as dyads that are with both informal carers and patients. Comparing single interviews (patient alone or informal carer alone) with dyadic interviews would be interesting in terms of the methodological difference and the outcome. This is important because the informal carers and patients identify themselves as one entity (symbiotic relationship) as seen in the substantive theory.

7.2.3 Implications for participants (informal carers and patients)

In section 7.2.1, it was argued how the Hospital High Vigilance theory could be operationalised in practice, management, and education. Whereas, in section 7.2.2 it was stated how it can be developed further by future research. However, reflective appraisal of the new substantive theory identified various implications also for the participants (informal carers and patients). The theory presented in

chapter 5 and in figure 6 in section 6.2, highlights concepts and categories which are easily understandable not only by health care professionals in the field but even by informal carers and patients (Glaser and Strauss 1967). The theory shows relevance because it possesses explanatory and predictive power for the participants (Glaser 1978). This was evident in chapter 5 whereas the participants' perspectives were privileged throughout the data collection and analysis. Furthermore, chapters 3 and 4 highlight the steps undertaken in developing and co-constructed a new substantive theory. On these premises, the following implications for participants include:

- The sudden onset of the CHF, the patient's unstable condition and the sudden admission and hospitalisation are extremely stressful moments for the informal carers (as highlighted in chapter 5). The Hospital High Vigilance theory acknowledges the vulnerability of the informal carers, the emotional reactions and the difficulties encountered by the informal carers during this period. Thus, it gives the informal carers insight on how they could cope or when they should seek help in such situations.
- The theory identified motivations for the informal carers in delaying admission (as seen in section 5.3.2) which could increase the patient's risk of mortality. As discussed in section 6.3.6 there are various reasons why an informal carer might delay an admission or seek help. By acknowledging and understanding these delays the informal carers could improve their communication with healthcare professionals to avoid these delays.
- The Hospital High Vigilance theory acknowledges and values the symbiotic relationship between the informal carers and the patients. This relationship evolves or changes during an emergency, admission, and hospitalisation. One of the reasons is that the social norms and operational structure of the hospital resulted in the disempowerment of the informal carers. The normal social norms that the informal carers had with the patient while at home could not be replicated in the hospital environment. By recognising this disempowerment and the disparity of the social norms between home and hospital, the informal carers could communicate their concerns and seek more information from the hospital staff rather than challenging the system.

7.3 Strength and Limitations of the study and subsequent personal learning

This section will highlight the strengths and limitations of the current research study. Despite the efforts to ensure methodological rigour as presented in Chapter 4, this study is impacted by limitations. Several of these limitations are related to the methodological decisions, while others are related to the general scope of the research study and my inexperience in conducting grounded theory research at the onset of the project. Therefore, the following is a methodological critique and the implications that this raises for my work. The following is also a reflection on the research journey, representing practical insight from a novice researcher using grounded theory for the first time (Charmaz 2014)

7.3.1 Critique of grounded theory research

A particular strength of this study is its use of grounded theory methodology, in which its methodology and methods give voice to the participants that feel invisible (Charmaz, 2014). Using grounded theory essential methods,⁴⁴ I tried to capture the complexity and ambiguity of the informal carers' experiences taking care of patients suffering from CHF during admission and hospitalisation. In fact, as stated by some participants of this study (see section 4.5.3), they expressed their feeling of liberation by talking about their informal care experiences during an interview. In addition, as discussed in Chapter 3, the philosophical orientation of constructivist grounded theory and its holistic, dynamic, contextual, and individualised approach made it an additional strength of this investigation. In other words, the grounded theory strategies helped me get started, stay involved and finish my project.

Grounded theory studies have been heavily criticised for their 'epistemological naivete, slipshod attention to data collection, questionable justification of small sample, presumed incompatibility of macro-questions, and hints of being unscientific' (Bryant and Charmaz 2007, p. 36). Nevertheless, despite these criticisms, grounded theory proved over the years to produce a large number of research and researchers who engage in qualitative inquiry (Bryant and Charmaz

⁴⁴ concurrent data generation and analysis, writing memos, theoretical sampling, constant comparative analysis, theoretical sensitivity, coding, identifying core category, theoretical integration and theory generation – Birks and Mills 2015, Charmaz 2014

2007). This research study is not immune to the above criticism; however, this subsection discusses such criticism in the context of the present study.

The notion of epistemological naivete could be derived from various debates that existed and still existed around grounded theory research. Conscious of the above criticism, chapter 3 of this thesis explained the study's ontological (relativist), epistemological (constructivist), and theoretical perspectives (symbiotic interactionism). Whereas chapter four clearly delineates the methodological decisions and procedures adopted. This helped position the current research to a specific school of grounded theory (Charmaz's constructivist grounded theory) and, consequently, use the appropriate methods. While in chapter 6, the Hospital High Vigilance theory was compared with studies and theoretical literature about vigilance and informal care from various perspectives. This helped mitigate the criticism that grounded theory studies emphasise the immediate contextual factors focusing on the experience rather than on the social process (McCann & Clark, 2003b). The Hospital High Vigilance theory emerged from the data presented in chapter 5 and their engagement with the literature (see chapter 6). The above procedures mitigate criticism that grounded theory is incapable of addressing the macro-sociological questions because it was an omission of early grounded theory authors when explaining methodological practices, rather than an inherent limitation of the grounded theory approach (Charmaz 2014).

Another important limitation of grounded theory is the tendency of producing low-level theories. These theories provide detailed explanations of an area but questionable ability to generically extend the explanation to other places and times (Charmaz 2006). This is because the theory is grounded in the data and the grounded theory coding process starts at a sentence level which tend to produce a rich and detailed theory (Urquhart 2013). Therefore, it could focus on the micro-phenomena rather than seeing the macro-structure of the social process involved (Urquhart 2013). However, the scope of this study was to generate a substantive theory that explains the social process in question in a clearly defined situation (Birks and Mills 2015). While acknowledging this limitation, efforts were made to scale the theory by relating it to the literature in chapter 6 (Urquhart 2013). Furthermore, the substantive theory generated through this study seems to have the potential to be elevated to a higher

conceptual level of formal theory by further future research (see Section 7.2.4). Nevertheless, the researcher recognises that the substantive theory generated is still descriptive in nature and needs work and more research in order to elevate it to a conceptual level.

Initial lack of research questions, not verifying previous theories or hypotheses, and no initial clear sample size are often criticised in grounded theory projects (Birks and Mills 2015). While I acknowledge that this was the case at the beginning of this study, the present thesis attempted to be transparent about how the initial research questions were conceived (Chapter 2), and about the sampling decisions during the different stages of the study (see Chapter 4). Purposive and theoretical sampling were used, which helped enhance the conceptual depth of the new substantive theory as the usage of only purposive sampling tends to produce descriptive findings (McCann and Clark 2003a). Conceptual depth was also enhanced by conducting data analysis and data collection concurrently and using successive inductive and deductive cycles which prevented the possibility of premature closure (McCann and Clark 2003b).

The constructivist approach to grounded theory has been highly criticised for allegedly imposing the researcher's views on the data instead of generating theory from the data (Glaser 2002). I recognise that this study is always one interpretation. For this study, interpretations of participants' experiences of informal care during admission and hospital of a patient suffering from CHF are represented by the participants' narratives and my personal experience as a nurse and an informal carer. Therefore, it is recognised that the readers of this study and other researchers may have their own interpretations and will, as a result, highlight different experiences and meanings. As discussed, and explained in Chapters 3 and 4, various measures were taken to prevent such imposition. These measures included:

- Using reflexivity,
- Writing memos about my background as a nurse and informal carer which might have influenced my views on the subject,
- Writing a reflective diary on how my perspectives shifted along the research journey,
- Prolonged engagement with data,

- Regular discussion and feedback from outsiders to the data and setting (my academic supervisors, colleagues, and conference audiences),
- Sharing the emerging theory with my academic supervisors and colleagues.

7.3.2 Limitations in the face-to-face interviews, recording and transcribing interviews

Like any other research method, face-to-face interviews have their limitations. For example, participants could portray inaccurate information of the experiences in examination because they might not want to give the wrong impression or appear ignorant in front of the researcher (Morris 2015). Another reason could be that as I am a healthcare professional, the participants might want to appease me instead of giving me what really happened or their views (Morris 2015). Moreover, doing interviews sometime after the event (admission and hospitalisation) could be affected by memory issues. Another limitation of the intensive face-to-face interviews can be the uncommunicative interviewee or participants taking over (especially since the first interviews were conducted with two participants – informal carers and patients) (Rubin and Rubin 2012).

The above problems highlight that the information given by the participants is usually challenging to check or verify (Morris 2015, Charmaz 2014). The above issues were partially resolved by continuously re-checking, verifying and probing during the interviews. I noted that having the informal carer and their relative do the interviews together helped them fill the gaps and verify certain events. As a researcher, I made it a must to make the participants as comfortable as possible by using some ice-breaking techniques, giving them time to read the information letter, answering all their questions truthfully, giving them a choice of where to conduct the interviews, providing them with an option to withdraw from the study any time, and giving them adequate time to decide to participate in the study. The above techniques appeared to put the participants in a comfortable situation to conduct the interviews and seemed to build trust between the researcher and the participants (Rubin and Rubin 2012). The participants verified this, as some said that these interviews gave them space and time to reflect on their experiences (informal caring during admission and hospitalisation) through the human connection between them and me. Because of this, it seemed that they gave an accurate and candid portrayal of their experiences and views (Rubin and Rubin

2012, Morris 2015, Charmaz 2014). In addition, after each interview, I made it a must to listen to the interview to reflect and use it as a teaching opportunity to refine my technique as an interviewer (see Memo Number 10082016 in Section 4.3.2). Furthermore, the interviews were transcribed by myself as a learning experience about my interview skills. However, I recognise that organising and setting up the interviews was time-consuming and required a lot of effort. There were instances when the participants cancelled at the last minute, refused to consent just before the interview started, or died suddenly.

Using an audio device to record the interviews helped me concentrate on the discussion during the interviews rather than frantically writing copious notes and remembering. Then I transcribed the interviews. Transcribing involves translations from an oral speech to a written text. However, when transcribing the interviews, the texts lose contexts such as body language, tone of voice, and pauses (Urquhart 2013, Kvale and Brinkman 2015). Using a video recorder in the interviews could have addressed the above problem because 'in the digital age, the importance of visual images, as opposed to text, cannot be denied' (Urquhart 2013 p. 69). However, this approach was discarded due to its obstructive and intrusive nature and the ethical implications of unintentionally capturing the personal items or safety issues of the participants' homes. To compensate for this shortcoming, I took field notes from the interview sessions and expanded as soon as possible, during or immediately after each interview session.

I recognise that transcription is expensive if you use a professional transcriber, and highly time-consuming if you do it yourself (Morris 2015). I chose to transcribe the interviews myself rather than using a professional transcriber. Using a professional transcriber could have saved me a lot of time and allowed me to concentrate on other tasks such as analysing the previous interviews. However, a professional transcriber could not be familiar with the medical terms, and a misinterpretation could occur. Furthermore, a professional transcriber might not be trained to deal with sensitive issues and could impose further ethical issues. By transcribing the interviews, I recognised that I learned much about my interviewing style and during transcribing, analysing the data was already started (Kvale and Brinkman 2015). On the other hand, as Kvale and Brinkman (2015) suggested, adopting a transcription procedure could have helped me move faster during the transcription.

7.3.3 Blurred boundaries between researcher and practitioner role and the implications of insider research

Since I was an informal carer myself and involved in the day-to-day care of various informal carers as a nurse, I was researching an aspect of informal caring that might have led me to take some elements for granted, such as interpreting what and the type of questions I asked (or did not ask) to the participants. Furthermore, being a nurse, some participants asked and sought advice about their illness and medications during the interviews. This made me constantly reflect and struggle between my nursing role and my researcher role.

My dual role as researcher and clinician, even if the participants were not cared for by myself could have led to situations where a clinician's "sense of clinical duty comes into apparent tension with ethics and methodological demands" (Hay-Smith et al. 2016 p. 2). As a result, role confusion and conflict can occur. In this study, my role as a nurse and researcher was both advantageous and disadvantageous. Familiarity with the research topic equipped me with "cultural intuition and insight" (Berger 2013 p 5) that assisted the process of data collection and analysis. For example, the cardiac area has its own distinct "language" and is peppered with jargon and abbreviations. Awareness of this enabled me to know not only what to ask and how to ask it but also to understand and probe participants' responses in a way that others without this knowledge might have missed. However, this "insider" position can simultaneously result in a researcher imposing their own biases and preconceptions onto the research, leading to a lack of critical distance and inability to "hear" other voices (Holloway & Galvin 2016).

Given this, one of the aims in preparing the interview guidelines, checklists, and reading about the interview process was to learn the interview techniques and be more aware of the skills required to be a researcher (see Section 4.3.2). In addition, other strategies were adopted to help me embrace the role of a researcher and minimise the insider researcher aspect. These included testing my interview skills with a colleague before the commencement of the data collection, peer debriefing (academic supervision), reflective diaries (methodological, data analysing and memoing), listening to the audiotaped recordings various times and using literature as conceptual levers. During the interviews, I constantly reminded the participants that I am a researcher rather

than a nurse. However, a distress protocol was devised and adopted (see Section 4.5.8) and referred to an appropriate professional for advice if needed. Finally, this ensured that the substantive theory emerged from the data and reflected the participants' views and experiences. However, I recognise that my views and experiences influenced and are intertwined with the participants' views and experiences in substantive theory. Chapter 3 and 4 represent a detailed audit trail of these and several other research decisions.

7.3.4 Limitations in transferability

This research study is based on the views and perspectives of informal carers taking care of their relatives suffering from CHF during admission and hospitalisation in Malta. This study was conducted in Malta with a small number of participants, limited to some extent by the characteristics of the participants who participated, the sampling technique employed, the majority of the informal care were women, and all the participants were white Maltese. Moreover, many of the described experiences were familiar to most of the participants, where gender-related differences were apparent. This was made clear in the findings. Due to the contextual differences between other chronic illnesses, other countries and other areas, even within the same hospital or country, broader generalisations undoubtedly require additional research. It makes it challenging to generalise and transfer the substantial theory beyond the context in which the data were elicited. Indeed, the main aim of the present study was to gain a deeper understanding of the informal care world within the specific chronic disease of a local general hospital, rather than studying contrasting cases and comparing results.

7.3.5 Limitations of theoretical sampling adopted

Theoretical sampling is a cornerstone of grounded theory; however, the practical aspects was problematic and limited (Dey 2007). Being a novice researcher in grounded theory was hard to know the categories were sufficiently grounded and therefore, identify when to stop and produce and analyse data. The application of theoretical sampling method was adopted using memo-writing and reflexivity. However, this required a lot of time and effort which is reflected the time elapsed from one set of data collection to another (See table 4 in section 4.2.1.3). Another problem identified during theoretical sampling was the unstable nature of the patient's chronic illness in which some participants (patients) died before I could

re-interview as part of the theoretical sampling. To avoid unnecessary distress to the informal carers who's relative had died, it was decided not to re-interview the previous participants and search for new participants which proved to be more time consuming. However, re-interviewing the informal carers when their loved one had died felt like dehumanising and disrespecting the participants by giving more importance to the study rather than to the participants. Ignoring such reciprocities and respect could have weakened the chance of obtaining honest data and not being truthful to myself as not only a researcher but even as healthcare worker and informal carer.

The purpose of this study and the research questions guiding this project was to target the factors related to informal carers taking care of their relatives during admission and hospitalisation after having an exacerbation episode of CHF at home. Such data were gathered by interviewing informal carers and their respective relatives. The informal carers' reaction to some attitudes and protocols of the hospital and healthcare professionals affected the relationship, contact time and the needs of the informal carers. While the data and the resulting substantive theory appear sufficient in addressing the research question, I acknowledge that an even more complete picture could have been obtained from the healthcare professionals themselves, and as such, this constitutes an important implication for future research arising from the present study (refer to Section 7.2.2).

7.4 Contribution to knowledge and concluding remarks

At the outset of the research study, the aim was to generate a substantive explanatory theory about the informal care during admission and hospitalisation of a patient suffering from CHF. This goal was justified because of the current shift of care from hospital to community care (where informal care is essential) and the lack of theories regarding the social process of informal care of a patient suffering from CHF during admission and hospitalisation. Before this study, it had been established that informal carers are an integral part of the patients' world suffering from CHF. Their reaction and coping mechanisms during admission and hospitalisation are essential to help the patient recover at home.

This study explored the underpinning methodology and research methods used to address the research questions presented in Chapter 2. Chapters 3 and 4

highlighted the methods and methodology used in this thesis. Various contributions to knowledge could be highlighted, which arose from applying the methods and methodology. One contribution that this thesis could provide to knowledge is how dyadic interviewing was used in a grounded theory study. Most of the studies use dyadic interviewing for examining the relationship between a couple or when the participants have an intellectual or cognitive impairment (Morgan et al. 2013, Morgan 2016). The main aim of this thesis was to construct a substantive theory about informal care during admission and hospitalisation of patients suffering from CHF and not to examine the relationship between informal carers and the patient. Furthermore, the patients were not intellectually or cognitively impaired. This thesis used dyadic interviewing in 11 interviews from 15 interviews (see table 4 in section 4.2.1.3) as the main means of collecting data. Dyadic interviews, as shown in section 4.3.4, were used for various reasons, mainly because of practical reasons (timesaving and safety reasons) and methodological reasons (to mimic and reflect the natural settings of the informal care, co-construction of theory between the participants and the researcher, alternative and multiple realities, simultaneous collection and analysis, and continuous comparisons). On the other hand, dyadic interviews raised no significant ethical issues or concerns, such as confidentiality or one participant dominating the interview. Most participants expressed their feelings of liberation by talking about their experiences during dyadic interviews. Therefore, this thesis contributed a practical way of using dyads interviews which is congruent with the ontological, epistemological, and theoretical perspectives of a constructivist grounded theory

Another contribution to knowledge is the usage of Maltese during the interviews but using English as means of coding and theory build-up. Language is central and pivotal to grounded theory for the participants to fully express themselves (Tarozzi 2011, Charmaz 2014). Therefore, the participants were allowed to talk in a language with which they were familiar. All the participants used Maltese in the interviews, and the transcripts were done in Maltese. However, the initial coding, focused coding, and theory build-up were written in English. I had to read the text and carefully analyse, interpret, and elaborate on what the participants were trying to say, which could be a powerful analytic resource. The translation was done only with the quotes used in the findings chapter. This is congruent with

the grounded theory's constant comparative method. However, some Maltese idioms and phrases could not be translated to English because of their language-culture link. Therefore, it was decided that some idioms or phrases were not translated, but an explanation in English was given. This process showed and contributed to the knowledge that Maltese can be used to build up a substantive theory in a grounded theory study.

Since its inception, diagramming has formed an integral part of grounded theory and was recommended by both original authors of grounded theory – Glaser and Strauss (Buckley and Warning 2013). However, as grounded theory evolved, controversies and debates arose on how and when to use diagrams. Strauss and Corbin (1998) recommend using diagrams and memos throughout the research. Glaser (1998) was against the excessive usage of diagrams throughout the research to avoid forcing the data. In contrast, Charmaz (2006) recommends using diagrams during theoretical development and analysis of the theory, which was rectified in 2014, where Charmaz (2014) acknowledges that diagrams could be used at all stages of analysis. These debates increased confusion among the researchers, which placed the diagramming in an unclear position on how to use it (Buckley and Warning 2013). Therefore, this thesis could help give knowledge of how diagrams could be used in a constructivist grounded theory. Given this, this thesis used various concepts of diagramming in different stages of the study. Pictures were used to elevate the initial codes to focus codes (see section 4.4.2.2, Figures 1 and 2, appendices 4 and 5, and table 4). Whereas diagrams using words were used to organize and build the substantive theory at a later stage of focus coding and theoretical coding (see figure 3, 4 and 5.)

The research findings were presented using a collection of interview transcripts, and research memos. A detailed discussion analysed how the constructivist grounded theory, which emerged from the data, was positioned amongst other literature. Recommendations for potential implications and further developments of the substantive theory were also reflected. Despite limitations, this study contributes insight and add knowledge into informal care during admission and hospitalisation by exploring in-depth social processes. These insights and knowledge are summarised below:

- The presence of informal carers near the relatives during admission and hospital is important but not enough,
- The informal carers and their relatives should be treated and assessed as dyads due to their symbiotic relationship,
- The new substantive theory identified the barriers in preventing the access of the informal carers to be near their relatives,
- Identified the physical, emotional, social and intellectual needs of the informal carers,
- Identified how the hospital environment and health care professionals could impact the informal carers' ability to take care of their relatives and thus affect the holistic care,
- Identified how admission and hospitalisation altered the informal carer's role, relationship, routines and assumptions,
- The preference and possible reasons why the informal carers and patients delay medical care and help during an exacerbation of CHF symptoms and thus favour the status quo,
- It gives additional knowledge and tools to understand and facilitate the well-being of informal carers in the situation of uncertainty and vulnerability,
- Identified how admission and hospitalisation but even the patient's instability affected the resilience of the informal carers,
- It could give a framework to health care professionals to assess and assist the informal carers in developing their resilience and coping capacity,
- The informal carers want to be involved in the care of their relatives (patients).

Therefore, applications of models such as FCC (Nethercott 1993), which enhance collaboration, negotiations and cooperation, can help address the above issues. However, implementing the FCC model (Nethercott 1993) is challenging due to inconsistencies in the interpretation of the above model. The Hospital High Vigilance model could address this challenge by giving context to the informal care of the patient suffering from CHF, as highlighted above.

In conclusion the common thread throughout this study was the informal carers' reaction when their relatives (patients) were admitted and hospitalised. This reaction was conceptualised as a Hospital High Vigilance stance based on their symbiotic relationship between the informal carers and the patient. The thesis argued that Hospital High Vigilance is a social process that could explain why the informal carers react to the admission and hospitalisation by helping and watching over their relatives to avoid harm. This is based on a long-term relationship between the informal carers and the patient, which is highly valued by both. The fear of losing this symbiotic relationship pushed the informal carers in being highly vigilant, and was affected by striving towards the status quo and striving towards resilience. Continuing to not empower and recognise informal carers during admission and hospitalisation of their relatives (patients) and the symbiotic relationship between them will eventually push the informal carers not to cope anymore. Understanding the informal carers by empowering them should be promoted to ensure quality care that meets the holistic health needs of the informal carers and the patients and is delivered by teams with a strong sense of staff well-being and professional fulfilment.

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Appendices

Help

The Carer

Do you care for someone suffering from a heart condition?

Would you be willing to share your experiences and thoughts?

I would like to hear from you!

I am an M. Phil-PhD student at the University of Brighton UK conducting a research study about the changing role of the informal carers taking care of their relatives suffering from Heart Failure.

Participating is completely voluntary and will involve a one-hour face-to-face interview.

For more info, please phone Paul Calleja on 99895986 or email

P.Calleja@brighton.ac.uk

Hospitalisation of Heart Failure patients: informal carers' changing role

Ngħinu lill- familjari/ħbieb

Int tieħu ħsieb xi ħadd li jbati minn kundizzjoni tal-qalb?

Lest/a li taqsam l-esperjenzi u l-ħsibijiet tiegħek?

Nixtieq nisma' mingħandek!

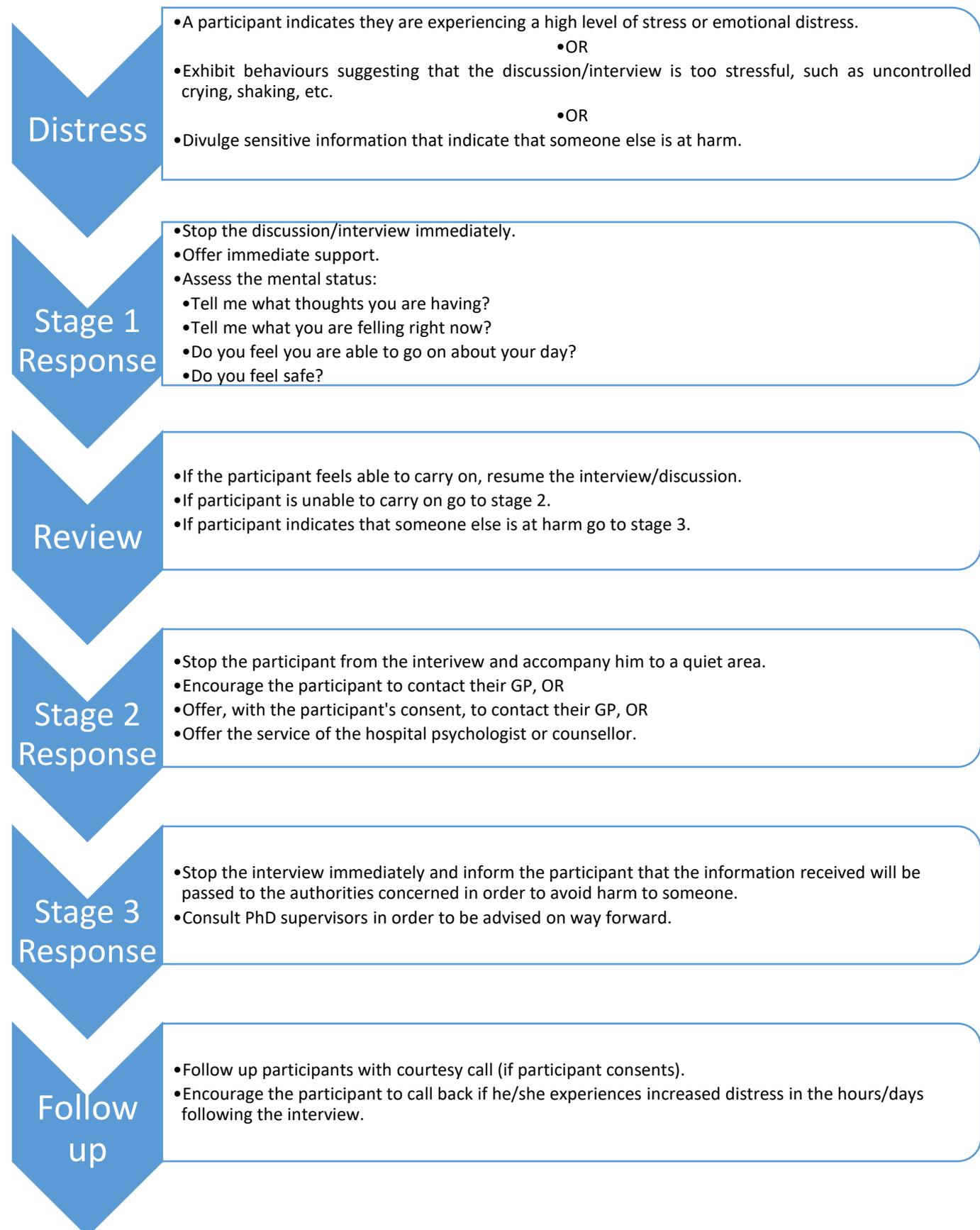
Jiena student tal-M.Phil/PhD fl-Università ta' Brighton fir-Renju Unit u qed nagħmel studju dwar ir-rowl tal-*carers* informali li jieħdu ħsieb il-qraba tagħhom li jbatu minn insuffiċjenza tal-qalb.

Il-parteciċipazzjoni hi kompletament volontarja u tinvolvi intervista ta' siegħa wicc imb'wicc.

Għal iktar informazzjoni ċempel lil Paul Calleja fuq 99895986 jew ibgħat email lil P.Calleja@brighton.ac.uk

Hospitalisation of Heart Failure patients: informal carers' changing role

Appendix 2: Distress protocol: interview (adapted from Draucker et al. 2009)



Appendix 3: Early example of comparing incident with incidents memo

Decision-making before hospitalisation - Describing Admission

AXL01

TBB02

JDP03

JGQ04

Incident 1

Incident 2

Incident 3

Incident 4

Properties of decision-making before hospitalisation:

- Delaying in care
- Fearing the unknown
- Waiting for long hours
- Dignity
- Pressuring
- Past Experiences

Memo: Throughout my career, I have noticed that sometimes patients come to the hospital very late, when the patient is nearly dying! From the interviews above, this issue was identified. This was confirmed in the interviews TBB02, JDP03 and JGQ04 but not in the interview AXL01. In the interview TBB02, the carer's primary concern in delaying her decision-making process to get her mother to the hospital was **waiting for long hours** on a stretcher without **dignity** in the AandE Department. In JGQ04, the carer's concern was the **long waiting time** in AandE, but it was also affected by the patient **pressuring** to remain at home rather than go to the hospital. Both interviews were affected by **past experiences**. The carer of TBB02 was a nurse and had cared for her father in the past. The wife in the interview, JGQ04, was affected by the patient's bad past experiences at the hospital. The patient himself stated this, but I need to expand more on how much past experiences affect decision-making in the early stage of admission. In the incident above of JDP03, a **delay in care** was identified of about 12 hours in which the patient did not seek help or go to the hospital. But I did not specifically explore the issue of why they took so long to seek medical help. Maybe the patient was trying to 'cope' with his illness in order to avoid or delay hospitalisation. Perhaps with the carer's support, he felt secure and tried to delay an inevitable admission. A more prompting and in-depth discussion with future participants will be sought. The patient in AXL01 was keen to phone for help/ambulance as soon as her symptoms manifested. The patient's primary reason

appears to be **fear** and that the carer panics a lot and does not know how to handle the situation.

Therefore, this data is inconclusive, and I need to seek more data. I need to ask and seek more data about when there is a delay; what are the reasons for the delay? Or what are the situations that help the carer decide when to seek medical help or hospital admission? How important is the patient's view for the carer regarding admission (as stated in the interview JGQ04)? I need to see the feelings and concerns of the carers during admission and how this affects decision-making. The carer in TBB02 expressed her worries that she might not see her back home again on every admission to the hospital. I need to get deeper into these thoughts and explore with other participants and with the same participants what is happening just before admissions, and why. Furthermore, I need to see what affects their decision-making before admission/in the acute phase? Who affects them? How? Why?

Appendix 4: Memo (11032017) of Diagram One

Explanation:

The soil and roots represent symbiosis and mutualism because they benefit through nutrients; earth and tree stay in place and complete each other.

The sun represents the life continuum; it is always there.

The clouds represent the chronic disease that hinders the growth of the tree

Rain and winds represent frequent hospitalisations and staff attitudes – too much rain and wind can harm the tree. But some rain can help to maintain and give nutrients to the roots.

Stem – represents dignity and value of self – strong and proud;

Falling leaves – losing control;

The inner bark of the tree – embracing the past and the present;

Leafless stems and branches – isolation that chronic disease brings;

Branches with a small number of leaves – holding on and letting go;

Twisted branches – lifestyle changes searching for light.

Although it is a nice representation, it does not explain everything the participants say in the interviews. It does not explain the multilayers of dignity and the social life that we live daily. I feel that the concepts are more connected with each other and are more complex.

I need to search for and draw something that explains the multilayers and the complexity of the social experiences, the cultural meanings and knowledge.

Appendix 5: Memo (12032017) of Diagram Two

The centre represents the core of everything, which is the type of relationship the carer builds with the patient based on the past and the present. It represents the symbiosis and mutualism that the carer built over time in which both the carer and patient benefit together. This relationship (dependency on each other) can explain why carers fear the future and the extreme notion of holding on to patients and not letting go. The participants showed contradictions when the patient was hospitalised. The carers experience mixed feelings and show signs of holding on and letting off. One participant manifested panic when the acute symptoms of heart failure manifested and phoned an ambulance but expressed anger when she was admitted. Bringing their loved ones to the hospital can be a sign of letting go, but it could be a sign of holding on because some participants (patients) expressed the wish to stay at home and went against the patient's desire. Some participants even expressed fear that they would not see them back home, and one of them even prayed to God not to let her relative die. Frequent hospitalisation could mean that the carer is not letting go of the patient and dying peacefully but getting to the hospital in fear of losing them. Even if the carer sees the patient getting worse due to their chronic disease, they prefer to get him to a hospital rather than dying peacefully at home. This issue of dying at home versus dying in hospital is a sensitive issue that I need to explore further in the interviews. I need to see what the carers think and feel about this subject. It would be interesting to compare this issue with the parenthood of a dying child and family-centred care theories.

Furthermore, carers stay long hours near the patient while hospitalised, which is not a sign of letting go but an extreme case of holding on. Moreover, the relationship between the patient and the carer is built on past experiences and connections with the present. This could be a sign or drawing upon past social experiences, cultural meanings and knowledge to engage in a mental dialogue about the implications of the present physical and social existence. All the interviews fail to mention the future; this could be interpreted as fear of the future, fear of being alone, fear of a spouseless future? I need to read about nostalgic theories, grieving theories, hopelessness theories and attachment/detachment theories. Do I need to be open to these aspects in future interviews?

These issues are built on the notion of symbiosis and mutualism. The participants show how they are connected with each other in a different manner. In the interviews,

some participants described their relationship uniquely. One carer described the patient as his “ghoqda” (knot), while another described their relationship as the cane of his life. Nevertheless, this relationship (symbiosis/mutualism) makes it more difficult during hospitalisation because of lower contact time due to limited visiting hours and the inability to care for each other at home. However, all the participants go out of their way to be near their loved ones. This could be interpreted as a sense of not letting go. Still, a possible explanation could be the relationship between the carer and the patient, which makes it difficult for them to leave their loved ones alone in the hospital. Although the long hours and a significant lifestyle change in the hospital could be interpreted as a burden, they continue to be near the patient and give them support and care. Participants even say that they support each other rather than one-way support. Even when they are relieved by other relatives or/and by hospital staff during hospitalisation, they still stay near the patient. What do I need to explore and expand in more detail in future interviews?

However, this type of relation comprises multiple layers and strata, interconnection and relay on others. The four main components of these layers are dignity, self-value, hospitalisation and chronic disease. Hospitalisation is a small part of this diagram but plays an important role and toll in the symbiotic/mutualistic relationship of the carer with the patient. Furthermore, hospitalisation means getting away from their home. Their home, for both the participants (carers and patients), means a place where they can be themselves, feel safe, and support their identity and relationships. During the interviews, it was noted that carers and patients similarly experience the loss of value self. Carers blame themselves and sometimes lose control of the situation. Fear of losing control can be attributed to something in which a person cannot manage or control the outcome of future events, thinking that something terrible could happen. In the interviews, the participants expressed fear of death and getting worse.

Furthermore, hospitalisation during the acute phase can be attributed to losing control because they are getting out of their everyday lifestyle, and the relatives cannot control the progress of the chronic illness. The participants saw the hospital environment, staff attitudes, fragmented care and routines as a limitation and a sense of losing control, and thus losing self. Sometimes, participants described how staff discredited or embarrassed them, affecting their dignity but not their relationship with the patient. Furthermore, hospitalisation can be attributed to social isolation since they spend a lot

of time near the patient, minimising the world's contacts during hospitalisation. But on the other hand, it can be a sign of the connection with the outer world to socialise more and see new people, which was not shown in any of the interviews. Maybe I did not explore in-depth for this.

Dignity can be explained as a social hierarchy closely tied to rank. While at home, the carer is at the top of the hierarchy since they do everything and decide for the patients. However, while in the hospital, the rank of the carer comes after the doctor, nurses and patient. They felt frustrated by this attitude, especially when the staff was disrespectful. This puts the carer in a position of vulnerability, whereas the hospital staff and attitudes are antipathic, prejudicial, arrogant and hostile. Socially, (Maltese) society expects that the carers take care of the patient while at home, but we do not wish and give them the chance to take care of them while in hospital. This is because of hospital norms such as limited visiting hours, different routines, and imposing routines. Dignity is based on values; in the interviews, values vary from participants being together through good moments and bad moments, being together for a very long time, and taking care of her mother because that is what she was thought and the value of supporting each other. Furthermore, dignity is enhanced and/or hindered by the relationships between the carer and the patient and external factors like hospital staff. In future interviews, I need to be more attentive and seek what hinders or enhances the dignity and value of the carers.

The outer circle is the build-up of all the continuous life experience, or it can be explained as the carer-hood? I need to search and read more about this.

Connection is highly dependent on which type of relationship exists between the carer and the patient. All the structure is connected and is multi-layered, with various themes and aspects of chronic life, dignity, the value of self, hospitalisation, and symbiosis/mutualism. These multiple and complex connections symbolise the social world that carers live in in today's society and how we interpret it.

Appendix 6: Memo (01102017) of Diagram Three

Characteristics of the main concepts – The sublimation of an Odyssey

- Odyssey
 - Onset of illness
 - Lifestyle change
 - Social isolation
 - Death
- Sublimation
 - Acuteness
 - Recurrent departing
 - Describing hospitalisation
 - Describing admission
 - Losing a valued self
 - Normalising illness
 - Normalising admission
- Twilight Zone (Limbo/Liminality)
 - Anger
 - Suppressed fear
 - Guilt
 - Anxiety
 - Vulnerability
 - Shock
 - Loneliness
 - Ambiguity
 - Confusion
 - Transitional
- Eternalism
 - Blocking time
 - Fearing the future
 - Letting go and holding on
 - Fearing death
 - Seeing no future
 - Living the moment

- Power Asymmetry
 - Losing control
 - Shifting power
 - Control locus
 - Incumbency
 - Tenacity
 - Dignity
 - Legitimacy
- Mutualism/Symbiosis
 - Complementing each other
 - Synergy
 - Participating
 - Collaborating
 - Being one
 - Dualism
 - Obsessively thinking of each other
 - Supporting each other
 - Attachment theory
- Built on
 - Building of the carer–patient rapport over time
- Effects
 - It affected the kind of experience (positive and negative) in the twilight zone.

Aim:

The aim and objectives of this study were to explore the social process and construction of the carers when they experience acute symptoms and consequently hospitalisation.

However, during the interviews, although specifically asked only about the hospitalisation, participants always went beyond that and described how it all began, the onset of the chronic heart failure. I noticed that I could never separate an event like hospitalisation from a more significant event which is chronic life (odyssey). Explaining the chronic life of a carer with their respective loved ones present is a

mammoth task because of the various aspects and dimensions that exist (diverse literature confirms this). But little or no literature was found explaining the social structures or conditions of what happens to the carers when the patients suffering from heart failure have an acute episode.

Defining the concepts:

Odyssey can be defined as a long journey usually marked by many as a change of fortune. This odyssey starts when the patient is diagnosed with CHF and will eventually end with the patient's death (or carer but absent in the interviews).

Sublimation in chemistry refers to a force in which the state of an object is raised from one status to another (from solid to gas). This requires a tremendous amount of energy. In psychology, it is a type of defence mechanism where socially unacceptable impulses are unconsciously transformed into socially acceptable behaviour or action. In the context of this study, this concept is bi-dimensional; the first dimension is the sudden onset of acute illness which will eventually result in admission, hospitalisation and recurrent departing as extraordinary events in the carers' chronic journey with the patient. The second dimension is the attempt of normalisation by the carers of admission, hospitalisation and recurrent departing, which generally are considered unacceptable or not normal for healthy people.

The twilight zone, limbo or liminality is referred to as a state of ambiguity, confusion or transition. This state will result in higher anxiety, anger, guilt, shock, vulnerability, fear and loneliness.

Eternalism can be defined as the past and the present being real while the future is not. In the odyssey, the carer and patient live the moment built on past experiences.

Power asymmetry refers to a state where differences in status exist between individuals. The individual in my context are carers, patients and hospital staff.

Mutualism/Symbiosis is defined as a mutual dependence and beneficial to both individuals or enhancing social well-being.

Linking the concepts:

The chronic life of a patient and their respective carer is characterised by various ups and downs, including gradual degenerative physical activity, social isolation, and a significant change in their lifestyle. During this odyssey, apart from a gradual degeneration of the health well-being, a sudden change from chronic to acute (sublimation) will occur, putting the carer in the twilight zone, limbo, or in a state of liminality (admission). However, the decision to sublimate and seek help (admission), or stay near the patient is taken upon past experiences and fear of death. There is a discrepancy in some carers' and patients' views. All carers are afraid of the future and live the moment by building on the past, whereas some patients do not fear death, and express themselves by stating that they live the moment but do not fear the future – death. In this twilight zone, three significant concepts affect this ambiguity, confusion, and transitional state: eternalism, power asymmetry, and mutualism/symbiosis. During the odyssey, concepts of eternalism, power asymmetry, and mutualism will always be present and constructed to build the carer–patient rapport. Still, they will mutate in the twilight zone, and they will affect the carers' levels of anxiety, shock, denial, vulnerability, anger and guilt.

During the odyssey, power is divided between carers and patients. In some interviews, the patient has the power, while in others, the carer has the power, but there is stability in which the carer/patient feels comfortable and normal. In the limbo state, the power is shifted between the carers and patient to a third person (hospital staff). This shifting of locus brings a lot of distress to the carer because they feel they are not in control anymore.

During this odyssey, the carer and patient invest and build upon their relationship to achieve a mutualistic or symbiotic relationship. Paradoxically, not only is the patient dependent on the carer, but the carers also depend on the patient. This dualism and being one entity is expressed frequently during the interviews by complementing each other, participating in their lives, supporting each other. This mutualism is threatened during the limbo phase because the carer and the patient must be separated, increasing their stress and anxiety. To compensate for this, the carers go out of their way to be near their loved ones all the time.

Questions to ask (from the data collected):

Do participants see hospitalisation as a major issue? Why?

Do participants normalise hospitalisation? If yes, why and how?

Is there any difference in their perceptions of the past, future and present between home and hospital?

What differences are there in power between the patient and carer while in hospital and at home?

How does their relationship change while in the hospital?

Need to see what is similar, different and absent in data – for sampling.

Appendix 7: Example of re-coding (attempt to refocus the initial codes and constant comparison)

Interview – AXL01	Initial Coding	Focus Coding	Memos
<p>Quote 1</p>	<p>explaining the admission sudden onset of the acute phase describing the symptoms.</p>	<p>Starting of a journey</p>	<p>The carer expressed fear and panic when seeing his loved one in the acute phase. Although the patient often went in and out of the hospital, he panicked the same, maybe because of seeing her in this unstable state.</p>
	<p>fearing death, fear of losing her leaving home to the hospital</p>	<p>Departing</p>	<p>So why did he panic? Maybe he had a fear of losing her and fear of death. The patient expressed her fear of death due to her worsening chronic symptoms. Her journey back to the hospital (she had a lot of admissions) started with fearing death that could have affected her carer.</p>
	<p>fearing the future seeing no future</p>	<p>Eternalism</p>	<p>How much do the chronic disease's views and acuteness affect the carer?</p> <p>In contrast with the above, the relative does not want her to stay or leave her at the hospital, and he gets angry.</p>

<p>Quote 2</p>	<p>holding on & letting off getting angry</p>	<p>Departuring</p>	<p>Their Odyssey from home to hospital starts with the acute onset of her chronic disease that triggers panic and fear, but also other emotions like anger and aggression because he will depart from her. An essential fact in this quote is the paradox of the carer: although he panics and gets her to the hospital, when the hospital tells them that she needs to stay for a while, he gets angry. He does not want to depart from her; he wants to enjoy her presence at home with him.</p>
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[Appendix 8: Informal carer participation information sheet \(English\)](#)

Informal Carer Participation Information Sheet (V4:18-12-2015) Hospitalisation of Heart Failure patients: Informal carers' changing role

I would like to invite you to take part in this research study. Before you decide, I would like you to understand why the research is being done and what your participation would involve. I will go through the information sheet with you and answer any questions you may have. This should take about 10 minutes. Talk to others about the study if you wish and ask me if there is anything that is not clear. You will be given time to think about whether you wish to take part before making a decision, and may take this sheet away with you.

What is the purpose of the study/project?

I am an M.Phil/PhD student at the University of Brighton, UK, and I am performing a study among patients with Heart Failure and their carers. I am interested in your views of how the carers' responsibilities change, especially during hospitalisation, and whether this could affect the decision-making process. The aim is to develop new processes to help the transition from hospital to home. To this effect, I would like to interview both the carer and the patient with Heart Failure.

Why have I been invited to participate?

I would like to interview you because you have lived the experience recently. Your views and experience will provide me with invaluable information and better understanding of the processes involved in transition from hospital to home. I am seeking 15 to 20 participants to participate in this research study.

Do I have to take part?

Participation in this study is completely voluntary, and you can decide not to participate without giving a reason. The treatment and care of your relative will not be changed if you wish to take part or not take part in the study.

What is expected from participants?

If you would like to take part, you will need to sign a consent form. I will interview both the carer and the patient with Heart Failure. You can choose to be interviewed with your relative or individually. This will take about 30 minutes to an hour for each interview. You can stop the interview at any time and only answer the questions that

you want to. You can choose the location of the interview. A room will be booked on the hospital grounds or on the university grounds or another place which is convenient for you, but that can ensure privacy and confidentiality.

The interview will be recorded using an audio voice recorder. During the interview, I will ask you about your experience and views of your relative's admission, hospitalisation, before discharge, on discharge and after discharge. Furthermore, I am interested to know how this experience could have affected your responsibilities. I will then type out our interview conversation. I may ask you for a follow-up interview to clarify points made during your initial interview. It will be your choice to decide if you want to participate in another interview.

Will I be paid for taking part?

You will not be paid for your participation in this research; however, reimbursement for travel expenses will be given to you.

What are the potential disadvantages or risks of taking part?

No significant risks associated with taking part in this study are anticipated. If you become upset or emotionally distressed by the types of questions asked during the interview, it will be paused or stopped.

What are the potential benefits of taking part?

You may not directly benefit from participating in this study. However, the information could be used to improve the service that you get from the hospital.

Will my taking part in the study/project be kept confidential?

When possible, everything that is said in the interview will remain confidential. If during the interview I am told that you and/or your relative are at risk or being treated unfairly and that could harm your well-being, I would need to refer this matter to an appropriate person. If possible, your name will not be revealed but I would talk to you about this first. Your name will not be mentioned in any thesis or reports that are written about the study. I will type the transcript, and the access to these transcripts will be restricted to me and my research supervisors. The tapes and transcripts from the interview will be stored separately and securely from a site file containing any written identifiable information in a locked filing cabinet in my office. Electronic data will be stored on a

password-protected computer. After completion of the study, tapes will be erased and personal data shredded. All other documentation will be archived for 10 years.

What will happen if I don't want to carry on with the study?

You can leave the study at any time if you no longer want to take part, without any consequences. However, the data you have contributed until the point of withdrawing might have already been analysed, and it might therefore not be possible to remove them.

What will happen to the results of the project?

The results from this project will be presented in writing in journal articles read by healthcare professionals. The results may also be presented at conferences to groups of healthcare professionals. At no time, however, will your name and personal details be used, or any identifying information revealed. All quotations from the interview transcription will be anonymised. You will be emailed or mailed a summary of the key findings once the study has finished.

Who is organising and funding the research?

The research is organised by University of Brighton, UK, and self-funded by the researcher.

Who has reviewed the study?

This research study has been reviewed and approved by the College of Life Health and Physical Science Ethics Committee, University of Brighton, UK. Furthermore, this research was reviewed and approved from the University of Malta Research Ethics Committee.

What if there is a problem?

If you have any questions or are unclear about anything, you can contact me at any time during the study for more information. Thank you for taking the time to read this information.

Paul Calleja

Researcher,

M.Phil/PhD Student

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If you have any concerns or complaints about the way the study is conducted, then please contact:

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Appendix 9: Informal carer participation information sheet (Maltese)

Dokument Informattiv għall-Carer Informali (V4:18-12-2015) ***Hospitalisation of Heart Failure patients: Informal carers' changing role***

Nixtieq nistednek tiegħu sehem f'dan l-istudju. Qabel ma tiddeċiedi jekk taċċettax li tiegħu sehem, nixtieqek tifhem għaliex qed issir din ir-riċerka u x'tinvolvi l-partiċipazzjoni tiegħek. Se ngħaddi miegħek dan id-dokument ta' informazzjoni u nirrispondi kull mistoqsija li jista' jkollok. Dan għandu jieħu madwar 10 minuti. Jekk trid, tista' tkellem lill-oħrajn dwar l-istudju u tista' qsi lili jekk hemm xi haġa li mhix ċara. Se tingħata żmien biex taħsibha dwar jekk tixtieqx tiegħu sehem qabel ma tiddeċiedi, u tista' tiegħu dan id-dokument miegħek.

X'inhu l-għan tal-istudju?

Jiena student tal-M.Phil/PhD mal-Università ta' Brighton u qed nagħmel studju fuq pazjenti li jbatu b'insuffiċjenza tal-qalb u dawk li jieħdu ħsiebhom. Jien interessat fil-fehmiet tiegħek dwar kif jinbidlu r-responsabbiltajiet tal-carers, speċjalment meta l-pazjent li jieħdu ħsieb ikun l-isptar, u jekk dan jistax jaffettwa l-proċess tat-teħid tad-deċiżjonijiet. L-għan huwa li jiġu żviluppati proċessi ġodda biex jgħinu t-tranzizzjoni mill-isptar għad-dar. Sabiex nagħmel dan nixtieq li nintervista kemm lill-carer u kif ukoll lill-pazjent li jbatu b'insuffiċjenza tal-qalb.

Għaliex ġejt mistieden/mistiedna niegħu sehem?

Nixtieq intervistak għaliex inti għext l-esperjenza reċentement. Il-fehmiet tiegħek u l-esperjenza tiegħek jagħtuni informazzjoni imprezzabbli u għarfien aħjar tal-proċessi involuti fit-tranzizzjoni mill-isptar għad-dar. Qed nfittex bejn 15 u 20 parteċipant biex jipparteċipaw f'dan l-istudju.

Għandi niegħdu sehem?

Il-partiċipazzjoni f'dan l-istudju hija kompletament volontarja u tista' tiegħu sehem meta jidherlek mingħajr ma tagħti raġuni. It-trattament u l-kura tal-qarib tiegħek mhux ser tinbidel jekk tiddeċiedi li tiegħu sehem jew li ma tiħux sehem fl-istudju.

X'inhu mistenni mill-partiċipanti?

Jekk tiddiciedi li tieħu sehem, ikollok bżonn tiffirma formola ta' kunsens. Jiena ser nintervista kemm lill-*carer* kif ukoll lill-pazjent li jbati b'insufficjenza tal-qalb. Tista' tagħżel li ssirlek intervista waħdek jew mal-qarib tiegħek. Kull intervista ddum bejn 30 minuta u siegħa. Tista' twaqqaf l-intervista xhin trid u twieġeb biss il-mistoqsijiet li tixtieq int. Tista' tagħżel il-post tal-intervista. Se jiġu bbukkjati kmamar fl-isptar jew fl-università jew f'xi post ieħor li jkun konvenjenti għalik imma li jista' jiżgura l-privatezza u l-kunfidenzjalità.

L-intervista se tiġi rrekordjata b'apparat diġitali. Fl-intervista, se nistaqsik dwar l-esperjenza tiegħek u l-fehmiet tiegħek dwar meta l-qarib tiegħek daħal l-isptar u meta sirt taf li kien ser joħroġ mill-isptar u wara li hareġ mill-isptar. Barra minn hekk, jiena interessat li nkun naf kif din l-esperjenza setgħet affettwat ir-responsabbiltajiet tiegħek. Imbagħad jiena ser nittapja din il-konverżazzjoni tagħna. Nista' nitlobok tieħu sehem f'intervista oħra biex niċċara xi punti li jkunu ħarġu mill-ewwel intervista miegħek. Mill-ġdid tkun tista' tiddeciedi int jekk tiħux sehem f'intervista oħra.

Hemm ħlas involut biex nieħu sehem?

M'hemmx ħlas għall-partecipazzjoni fl-istudju, imma l-ispejjeż tal-ivvjaggar jingħatawlek lura.

X'inhuma r-riskji jew l-iżvantaġġi potenzjali jekk nieħu sehem?

M'humiex mistennija riskji partikolari jekk tieħu sehem f'dan l-istudju. Jekk waqt l-intervista tibda tħossok skomdu/a jew emozzjonat/a minħabba l-mistoqsijiet li nkun qed nistaqsik, l-intervista titwaqqaf għal ftit ħin jew għal kollox.

X'inhuma l-beneficċji potenzjali jekk nieħu sehem?

Inti jaf ma tibbenefikax direttament mill-partecipazzjoni f'dan l-istudju. Madankollu, l-informazzjoni li tingħabar tista' tintuża biex jittejjeb is-servizz li tingħata mill-isptar.

Is-sehem tiegħi f'dan l-istudju / proġett jinżamm kunfidenzjali?

Meta possibbli dak kollu li jkun ntqal fl-intervista ser jibqgħa kunfidenzjali . Jekk matul l-intervista niġi infurmat li int jew xi ħadd ieħor qegħdin f'xi forma ta riskju, ikolli bżonn nirreferi din il-kwistjoni mal-persuna xierqa. Sa fejn hu possibbli, ismek mhux ser jiġi żvelat iżda nitkellem miegħek dwar dan l-ewwel. Ismek mhux se jissemma fl-ebda teži

jew rapporti li se jinkitbu dwar l-istudju. Jiena se nittapja l-konverżazzjoni tal-intervisti u jien biss se jkollu aċċess għalihom. Ir-rekordings, it-traskrizzjonijiet tal-intervista u kwalunkwe informazzjoni identifikabbli se jinżammu msakkra f'post sigur fl-ufficju tiegħi. Id-data elettronika se tinħażen f'kompjuter u se tkun protetta b'*password*. Wara li jitlesta l-istudju, it-*tapes* se jithassru u d-data personali titqatta'. Id-dokumentazzjoni l-oħra kollha se tiġi arkivjata għal 10 snin.

X'jiġri jekk ma nrridx ikompli bl-istudju?

Inti tkun tista' twaqqaf is-sehem tiegħek f'dan l-istudju meta jidhirlek mingħajr ebda konsegwenzi. Madankollu, id-data li tkun ikkontribwejt sa dak il-ħin se tkun diġà ġiet analizzata u integrata fl-istudju u għalhekk ma tkunx tista' titneħħa.

X'se jiġri mir-riżultati tal-proġett?

Ir-riżultati minn dan il-proġett se jiġu pprezentati bil-miktub f'artikli f'rivisti li jinqraw minn professjonisti tal-ħarsien tas-saħħa. Ir-riżultati jistgħu wkoll jiġu pprezentati f'konferenzi għal gruppi ta' professjonisti tal-ħarsien tas-saħħa. Madankollu, fl-ebda ħin m'huma se jidhru ismek u d-dettalji personali jew kwalunkwe informazzjoni oħra li tista' tixxef l-indentità tiegħek. Il-kwotazzjonijiet kollha mit-traskrizzjoni tal-intervista ser ikunu anonimi. Ser tintbagħtlek taqsira tas-sejbiet prinċipali bil-posta normali jew elektronika ladarba l-istudju jkun lest.

Min qed jorganizza u jħallas għar-riċerka?

Ir-riċerka hija organizzata mill-Università ta' Brighton fir-Renju Unit u mħallsa mir-riċerkatur.

Min irveda dan l-istudju?

Dan l-istudju ta' riċerka ġie rivedut u approvat mill-Kumitat tal-Etika tal-Kulleġġ tal-Kulleġġ tax-Xjenzi Fiżiċi, tas-Saħħa u tal-Ħajja tal-Università ta' Brighton fir-Renju Unit. Barra minn hekk, din ir-riċerka kienet riveduta u approvata mill-Kumitat tal-Etika fir-Riċerka tal-Università ta' Malta.

X'jiġri jekk ikun hemm xi problema?

Jekk ikollok xi mistoqsijiet jew ikun hemm affarijiet li m'initix konvint minnhom, tista' tikkuntattjani u titlobni aktar informazzjoni meta trid matul l-istudju. Grazzi tal-hin li hadt biex taqra din l-informazzjoni.

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Jekk ikollok xi problemi jew ilmenti dwar il-mod ta' kif qed jitwettaq dan l-istudju jekk jogħġbok ikkuntattja lil:

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Appendix 10: Patients participant information sheet - Maltese

Dokument Informattiv għall-Pazjent (v4:18-12-2015)

Hospitalisation of Heart Failure patients: Informal carers' changing role

Nixtieq nistednek tieġu sehem f'dan l-istudju. Qabel ma tiddeċiedi jekk taċċettax li tieġu sehem, nixtieqek tifhem għaliex qed issir din ir-riċerka u x'tinvolvi l-partiċipazzjoni tiegħek. Se ngħaddi miegħek dan id-dokument ta' informazzjoni u nirrispondi kull mistoqsija li jista' jkollok. Dan għandu jieġu madwar 10 minuti. Jekk trid, tista' tkellem lill-oġrajn dwar l-istudju u tista'qsi lili jekk hemm xi ħaġa li mhix ċara. Se tingħata żmien biex taħsibha dwar jekk tixtieqx tieġu sehem qabel ma tiddeċiedi, u tista' tieġu dan id-dokument miegħek.

X'inhu l-għan tal-istudju?

Jiena student tal-M.Phil/PhD mal-Università ta' Brighton u qed nagħmel studju fuq pazjenti li jbatu b'insuffiċjenza tal-qalb u dawk li jieġdu ħsiebhom. Jien interessat li-fehmiet tiegħek dwar kif jinbidlu r-responsabbiltajiet tal-carers, speċjalment meta l-pazjent li jieġdu ħsieb ikun l-isptar, u jekk dan jistax jaffettwa l-proċess tat-teħid tad-deċiżjonijiet. L-għan huwa li jiġu żviluppati proċessi ġodda biex jgħinu t-tranzizzjoni mill-isptar għad-dar. Sabiex nagħmel dan nixtieq li nintervista kemm lill-carer u kif ukoll lill-pazjent li jbatu b'insuffiċjenza tal-qalb.

Għaliex ġejt mistieden/mistiedna nieġu sehem?

Nixtieq intervistak għaliex inti għext l-esperjenza reċentement. Il-fehmiet tiegħek u l-esperjenza tiegħek jagħtuni informazzjoni imprezzabbli u għarfien aħjar tal-proċessi involuti fit-tranzizzjoni mill-isptar għad-dar. Qed nfittex bejn 15 u 20 partiċipant biex jipparteċipaw f'dan l-istudju.

Għandi nieġdu sehem?

Il-partiċipazzjoni f'dan l-istudju hija kompletament volontarja u tista' tieqaf tieġu sehem meta jidherlek mingħajr ma tagħti raġuni. It-trattament u l-kura tal-qarib tiegħek mhux ser tinbidel jekk tiddeċiedi li tieġu sehem jew li ma tiħux sehem fl-istudju.

X'inhu mistenni mill-partiċipanti?

Jekk tiddeciedi li tiehu sehem, ikollok bzonn tiffirma formola ta' kunsens. Jiena se nintervista kemm lill-*carer* kif ukoll lill-pazjent li jbati b'insufficjenza tal-qalb. Tista' taghzel li ssirlek intervista waħdek jew mal-qarib tieghek. Kull intervista ddum bejn 30 minuta u siegħa. Tista' twaqqaf l-intervista xhin trid u twiegeb biss il-mistoqsijiet li tixtieq int. Tista' taghzel il-post tal-intervista. Se jiġu bbukkjati kmamar fl-isptar jew fl-università jew f'xi post ieħor li jkun konvenjenti għalik imma li jista' jiżgura l-privatezza u l-kunfidenzjalità.

L-intervista se tiġi rrekordjata b'apparat diġitali. Fl-intervista, se nistaqsik dwar l-esperjenza u l-fehmiet tieghek dwar meta dħalt l-isptar u meta sirt taf li kont se toħroġ mill-isptar u wara li ħriġt mill-isptar. Barra minn hekk, jiena interessat dwar kif din l-esperjenza setgħet affettwat ir-responsabbiltajiet tal-*carer* informali tieghek. Imbagħad jiena ser nittapja din il-konverżazzjoni tagħna. Nista' nitlobok tiehu sehem f'intervista oħra biex niċċara lxi punti li jkunu ħarġu mill-ewwel intervista mieghek. Mill-ġdid tkun tista' tiddeciedi int jekk tiħux sehem f'intervista oħra.

Hemm ħlas involut biex niehu sehem?

M'hemmx ħlas għall-partecipazzjoni fl-istudju, imma l-ispejjeż tal-ivvjaggar jingħatawlek lura.

X'inhuma r-riskji jew l-iżvantaġġi potenzjali jekk niehu sehem?

M'humiex mistennija riskji partikolari jekk tiehu sehem f'dan l-istudju. Jekk waqt l-intervista tibda tħossok skomdu/a jew emozzjonat/a minħabba l-mistoqsijiet li nkun qed nistaqsik, l-intervista titwaqqaf għal ftit ħin jew għalkollox.

X'inhuma l-benefiċċji potenzjali jekk niehu sehem?

Inti jaf ma tibbenefikax direttament mill-partecipazzjoni f'dan l-istudju. Madankollu, l-informazzjoni li tingħabar tista' tintuża biex jittejjeb is-servizz li tingħata mill-isptar.

Is-sehem tiegħi f'dan l-istudju / proġett jinżamm kunfidenzjali?

Meta possibbli dak kollu li jkun ntqal fl-intervista ser jibqgħa kunfidenzjali . Jekk matul l-intervista niġi infurmat li int jew xi ħadd ieħor qegħdin f'xi forma ta riskju, ikolli bzonn nirreferi din il-kwistjoni mal-persuna xierqa. Sa fejn hu possibbli, ismek mhux ser jiġi żvelat iżda nitkellem mieghek dwar dan l-ewwel. Ismek mhux se jissemma fl-ebda teži

jew rapporti li se jinkitbu dwar l-istudju. Jiena se nittapja l-konverżazzjoni tal-intervisti u jien biss se jkollu aċċess għalihom. Ir-rekordings, it-traskrizzjonijiet tal-intervista u kwalunkwe informazzjoni identifikabbli se jinżammu msakkra f'post sigur fl-ufficju tiegħi. Id-data elettronika se tinħażen f'kompjuter u se tkun protetta b'*password*. Wara li jitlesta l-istudju, it-*tapes* se jithassru u d-data personali titqatta'. Id-dokumentazzjoni l-oħra kollha se tiġi arkivjata għal 10 snin.

X'jiġri jekk ma nrridx ikompli bl-istudju?

Inti tkun tista' twaqqaf is-sehem tiegħek f'dan l-istudju meta jidherlek mingħajr ebda konsegwenzi. Madankollu, id-data li tkun ikkontribwejt sa dak il-ħin se tkun diġà ġiet analizzata u integrata fl-istudju u għalhekk ma tkunx tista' titneħħa.

X'se jiġri mir-riżultati tal-proġett?

Ir-riżultati minn dan il-proġett se jiġu ppreżentati bil-miktub f'artikli f'rivisti li jinqraw minn professjonisti tal-ħarsien tas-saħħa. Ir-riżultati jistgħu wkoll jiġu ppreżentati f'konferenzi għal gruppi ta' professjonisti tal-ħarsien tas-saħħa. Madankollu, fl-ebda ħin m'huma se jidhru ismek u d-dettalji personali jew kwalunkwe informazzjoni oħra li tista' tixxef l-indentità tiegħek. Il-kwotazzjonijiet kollha mit-traskrizzjoni tal-intervista ser ikunu anonimi. Ser tintbagħtlek taqsira tas-sejbiet prinċipali bil-posta normali jew elektronika ladarba l-istudju jkun lest.

Min qed jorganizza u jħallas għar-riċerka?

Ir-riċerka hija organizzata mill-Università ta' Brighton fir-Renju Unit u mħallsa mir-riċerkatur.

Min irveda dan l-istudju?

Dan l-istudju ta' riċerka ġie rivedut u approvat mill-Kumitat tal-Etika tal-Kulleġġ tal-Kulleġġ tax-Xjenzi Fiżiċi, tas-Saħħa u tal-Ħajja tal-Università ta' Brighton fir-Renju Unit. Barra minn hekk, din ir-riċerka kienet riveduta u approvata mill-Kumitat tal-Etika fir-Riċerka tal-Università ta' Malta.

X'jiġri jekk ikun hemm xi problema?

Jekk ikollok xi mistoqsijiet jew ikun hemm affarijiet li m'initix konvint minnhom, tista' tikkuntattjani u titlobni aktar informazzjoni meta trid matul l-istudju. Grazzi tal-hin li hadt biex taqra din l-informazzjoni.

Paul Calleja
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Email: P.Calleja@brighton.ac.uk

Jekk ikollok xi problemi jew ilmenti dwar il-mod ta' kif qed jitwettaq dan l-istudju jekk jogħġbok ikkuntattja lil:

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Appendix 11: Patients participant information sheet – English

Patient Participation Information Sheet (V4:18-12-2015)

Hospitalisation of Heart Failure patients: Informal carers' changing role

I would like to invite you to take part in this research study. Before you decide, I would like you to understand why the research is being done and what your participation would involve. I will go through the information sheet with you and answer any questions you may have. This should take about 10 minutes. Talk to others about the study if you wish, and ask me if there is anything that is not clear. You will be given time to think about whether you wish to take part before making a decision, and may take this sheet away with you.

What is the purpose of the study/project?

I am an M.Phil/PhD student at the University of Brighton, UK, and I am performing a study among patients with Heart Failure and their carers. I am interested in your views of how the carers' responsibilities change, especially during hospitalisation, and whether this could affect the decision-making process. The aim is to develop new processes to help the transition from hospital to home. To this effect, I would like to interview both the carer and the patient with Heart Failure.

Why have I been invited to participate?

I would like to interview you because you have lived the experience recently. Your views and experience will provide me with invaluable information and better understanding of the processes involved in transition from hospital to home. I am seeking 15 to 20 participants to participate in this research study.

Do I have to take part?

Participation in this study is completely voluntary, and you can decide not to participate without giving a reason. Your treatment and care will not be changed if you wish to take part or not take part in the study.

What is expected from participants?

If you would like to take part, you will need to sign a consent form. I will interview both the carer and the patient with Heart Failure. You can choose to be interviewed with your relative or individually. This will take about 30 minutes to an hour for each interview. You can stop the interview at any time and only answer the questions that

you want to. You can choose the location of the interview. A room will be booked on the hospital grounds or on the university grounds or another place which is convenient for you, but that can ensure privacy and confidentiality.

The interview will be recorded using an audio voice recorder. During the interview, I will ask you about your experience and views of your admission, hospitalisation, before discharge, on discharge and after discharge. Furthermore, I am interested to know how this experience could have affected your informal carer responsibilities. I will then type out our interview conversation. I may ask you for a follow-up interview to clarify points made during your initial interview. It will be your choice to decide if you want to participate in another interview.

Will I be paid for taking part?

You will not be paid for your participation in this research; however, reimbursement for travel expenses will be given to you.

What are the potential disadvantages or risks of taking part?

No significant risks associated with taking part in this study are anticipated. If you become upset or emotionally distressed by the types of questions asked during the interview, it will be paused or stopped.

What are the potential benefits of taking part?

You may not directly benefit from participating in this study. However, the information could be used to improve the service that you get from the hospital.

Will my taking part in the study/project be kept confidential?

When possible, everything that is said in the interview will remain confidential. If during the interview I am told that you and/or your relative are at risk or being treated unfairly and that could harm your well-being, I would need to refer this matter to an appropriate person. If possible, your name will not be revealed but I would talk to you about this first. Your name will not be mentioned in any thesis or reports that are written about the study. I will type the transcript, and the access to these transcripts will be restricted to me and my research supervisors. The tapes and transcripts from the interview will be stored separately and securely from a site file containing any written identifiable information in a locked filing cabinet in my office. Electronic data will be stored on a

password-protected computer. After completion of the study, tapes will be erased and personal data shredded. All other documentation will be archived for 10 years.

What will happen if I don't want to carry on with the study?

You can leave the study at any time if you no longer want to take part, without any consequences. However, the data you have contributed until the point of withdrawing might have already been analysed, and it might therefore not be possible to remove them.

What will happen to the results of the project?

The results from this project will be presented in writing in journal articles read by healthcare professionals. The results may also be presented at conferences to groups of healthcare professionals. At no time, however, will your name and personal details be used, or any identifying information revealed. All quotations from the interview transcription will be anonymised. You will be emailed or mailed a summary of the key findings once the study has finished.

Who is organising and funding the research?

The research is organised by University of Brighton, UK, and self-funded by the researcher.

Who has reviewed the study?

This research study has been reviewed and approved by the College of Life Health and Physical Science Ethics Committee, University of Brighton, UK. Furthermore, this research was reviewed and approved from the University of Malta Research Ethics Committee.

What if there is a problem?

If you have any questions or are unclear about anything, you can contact me at any time during the study for more information. Thank you for taking the time to read this information.

Paul Calleja

Researcher,

M.Phil/PhD Student

Mob: +356 99895985

Email: P.Calleja@brighton.ac.uk

If you have any concerns or complaints about the way the study is conducted, then please contact:

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Deputy Head of School

School of Health Sciences

The University of Brighton

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My supervisory team for this project is:

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University of Brighton,

Room 132 Mayfield House,

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UK

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Dr Nina Dunne – M.Phil/PhD supervisor

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Appendix 12: Informal carer consent form – Maltese

Hospitalisation of Heart Failure patients: Informal carers' changing role

Formola ta' Kunsens għall-*Carer* Informali (V3:18-12-2015)

Niżżel l-
inizjali jew
immarka
l-kaxxa

Ir-riċerkatur fissirli l-istudju u qrajt il-paġna bl-informazzjoni **(V4:18-12-2015)**. Nifhem dak li qed nintalab nagħmel u naqbel li niehu sehem f'dan l-istudju

Ir-riċerkatur spjega għas-sodisfazzjon tiegħi l-iskop tal-istudju u r-riskji possibbli.

Nifhem li dan il-proġett ta' riċerka jinvolvi li nwieġeb mistoqsijiet u li l-konverżazzjoni tiegħi mar-riċerkatur se tiġi rrekordjata.

Nifhem li jekk niżvela ħsara jew ħsara potenzjali jew negliġenza, il-materja tiġi diskussa ma' persuna kompetenti.

Naqbel li r-riċerkatur jerga' jikkuntattjani jekk ikun jixtieq jiċċara xi punti. Nifhem li għandi d-dritt inwaqqaf is-sehem tiegħi fl-istudju meta jidhirli u li m'iniex obligat/a li naċċetta li niehu sehem f'intervista oħra.

Nifhem li r-riżultati tal-istudju se jiġu ppubblikat f'artikli u pprezentati f'konferenzi, mingħajr ma jidhru l-ismijiet tal-parteciċipanti.

Nifhem li nista' nirtira mill-istudju meta jidhirli mingħajr konsegwenzi u mingħajr ma jkolli nagħti raġuni.

Naqbel li jekk nirtira mill-istudju, id-dejta miġbura sa dak iż-żmien tista' tintuża mir-riċerkatur għall-għanijiet deskritti fil-paġna bl-informazzjoni

Naqbel li nieħdu sehem f'din riċerka li hija dwar is-suġġett imsemmi hawn fuq

Isem

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Jekk għandek xi problemi jew ilment dwar kif qed isir dan l-istudju, jekk jogħġbok ikkuntattja lil:

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Appendix 13: Informal carer consent form – English

Informal Carer Consent Form (V3:18-12-2015)

Hospitalisation of Heart Failure patients: Informal carers' changing role

Please
initial or
tick box

I have had the research project explained to me, and I have also read the participant information sheet (V4:18-12-2015). I understand what is being asked of me, and I agree to participate in this study.

The researcher has explained to my satisfaction the purpose of the study and the possible risks involved.

I am aware that this research project involves answering questions that will be recorded on an audio-recorded device.

I understand that should I disclose actual or potential harm or poor practice, this matter will be discussed with an appropriate professional.

I agree to be contacted if the researcher wishes to follow up any issues. I understand I have the right to withdraw from the study at any point and that I am not obliged to agree to be re-interviewed.

I understand that the findings from the study will be published in journal articles and presented at conferences, but interview quotations will be anonymised.

I understand that I am free to withdraw from the research at any time without giving a reason and without incurring consequences from doing so.

I agree that should I withdraw from the study, the data collected up to that point may be used by the researcher for the purposes described in the information sheet.

I agree to take part in this research which is about Hospitalisation of Heart Failure patients: Informal carers' changing role.

Name

Signed Date

Researcher – Paul Calleja - Mob: +356 99895985 Email: P.Calleja@brighton.ac.uk

Signed Date

Supervisor - Dr Josef Trapani – tel: 23401166 Email: josef.trapani@um.edu.mt

Signed Date

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Appendix 14: Patient consent form – Maltese

Hospitalisation of Heart Failure patients: Informal carers' changing role

Formola ta' Kunsens għall-Pazjent (V3:18-12-2015)

Niżżel l-
inizjali jew
immarka
l-kaxxa

Ir-riċerkatur fissirli l-istudju u qrajt il-paġna bl-informazzjoni **(V4:18-12-2015)**. Nifhem dak li qed nintalab nagħmel u naqbel li niehu sehem f'dan l-istudju

Ir-riċerkatur spjega għas-sodisfazzjon tiegħi l-iskop tal-istudju u r-riskji possibbli.

Nifhem li dan il-proġett ta' riċerka jinvolvi li nwieġeb mistoqsijiet u li l-konverżazzjoni tiegħi mar-riċerkatur se tiġi rrekordjata.

Nifhem li jekk niżvela ħsara jew ħsara potenzjali jew negliġenza, il-materja tiġi diskussa ma' persuna kompetenti.

Naqbel li r-riċerkatur jerga' jikkuntattjani jekk ikun jixtieq jiċċara xi punti. Nifhem li għandi d-dritt inwaqqaf is-sehem tiegħi fl-istudju meta jidhirli u li m'iniex obligat/a li naċċetta li nieħu sehem f'intervista oħra.

Nifhem li r-riżultati tal-istudju se jiġu ppubblikat f'artikli u pprezentati f'konferenzi, mingħajr ma jidhru l-ismijiet tal-partecipanti.

Nifhem li nista' nirtira mill-istudju meta jidhirli mingħajr konsegwenzi u mingħajr ma jkolli nagħti raġuni.

Naqbel li jekk nirtira mill-istudju, id-dejta miġbura sa dak iż-zmien tista' tintuża mir-riċerkatur għall-għanijiet deskritti fil-paġna bl-informazzjoni

Naqbel li nieħdu sehem f'din riċerka li hija dwar is-sugġett imsemmi hawn fuq

Isem

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Firma Data

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Firma Data

Jekk għandek xi problemi jew ilment dwar kif qed isir dan l-istudju, jekk jogħġbok ikkuntattja lil:

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Appendix 15: Patient consent form – English

Patient Consent Form (V3:18-12-2015)

Hospitalisation of Heart Failure patients: Informal carers' changing role

Please
initial or
tick box

I have had the research project explained to me and I have also read the participant information sheet (**V4:18-12-2015**). I understand what is being asked of me and I agree to participate in this study.

The researcher has explained to my satisfaction the purpose of the study and the possible risks involved.

I am aware that this research project involves answering questions that will be recorded on an audio-recorded device.

I understand that should I disclose actual or potential harm or poor practice, this matter will be discussed with an appropriate professional.

I agree to be contacted if the researcher wishes to follow up any issues. I understand I have the right to withdraw from the study at any point and that I am not obliged to agree to be re-interviewed.

I understand that the findings from the study will be published in journal articles and presented at conferences, but interview quotations will be anonymised.

I understand that I am free to withdraw from the research at any time without giving a reason and without incurring consequences from doing so.

I agree that should I withdraw from the study, the data collected up to that point may be used by the researcher for the purposes described in the information sheet.

I agree to take part in this research which is about Hospitalisation of Heart Failure patients: Informal carers' changing role.

Name

Signed Date

Researcher – – Paul Calleja - Mob: +356 99895985 Email: P.Calleja@brighton.ac.uk

Signed Date

Supervisor - Dr Josef Trapani – tel: 23401166 Email: josef.trapani@um.edu.mt

Signed Date

If you have any concerns or complaints about the way the study is conducted, then please contact;

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Appendix 16: Agenda għall-Intervista mal-carer informali - Maltese

Mistoqsijiet tal-bidu

- Jekk jogħġbok għidli x'kien għara meta l-qarib tiegħek daħal l-isptar?
- Kif kienet l-esperjenza? Tiftakar x'kont qed taħseb dak il-ħin? Kien hemm xi ħadd li influwenza l-azzjonijiet tiegħek? Jekk iva, min u kif influwenzak?
- Tista' tiddeskrivi l-avvenimenti li wasslu lill-qarib tiegħek jiddaħhal l-isptar?
- Liema fatturi kkontribwew għal dan l-avveniment?
- Kif il-bzonn tal-isptar affettwa deċiżjonijiet tiegħek?
- Kif kienet il-ħajja tiegħek qabel ma' daħal l-isptar? Kif inbidlet meta kien l-isptar?
- Tista' tgħidli dwar ħsibijiet tiegħek u x'ħassejt meta sirt taf li l-qarib tiegħek se jinżamm l-isptar?

Mistoqsijiet intermedji

- X'kont taf fuq:
 - Kif tkampa meta tkun id-dar?
 - Ir-rwol tiegħek?
 - L-appuntamenti wara li l-qarib tiegħek joħroġ mill-isptar?
- Tista' tgħidli dwar il-ħsibijiet tiegħek u kif ħassejtek meta:
 - Il-qarib tiegħek kien l-isptar?
 - Il-konsulent qallek li l-qarib tiegħek jista' jmur id-dar?
 - Eżatt qabel ma l-qarib tiegħek mar id-dar?
 - Meta l-qarib tiegħek mar id-dar?
- Min kien involut? Meta? Kif kien/u involut/i?
- Tista' tiddeskrivi gurnata tipika (tiegħek u tal-qarib tiegħek)
 - Qabel ma daħal l-isptar?
 - Fl-isptar?
 - Eżatt wara li ħareġ mill-isptar?
- Min għenek l-iktar matul dan iż-żmien? Kif għenek/għenitek?
- Meta tħares lura lejn din l-esperjenza, liema avvenimenti laqtuk l-aktar? Tista' tiddiskrivihom? Kif affettwawk dawn l-avvenimenti? Kif irreaġixxajt għal dawn l-avvenimenti/sitwazzjonijiet?
- X'taħseb li għenek l-aktar f'din l-esperjenza? Liema kienu l-problemi li Itqajt magħhom? Tista' żżid xi haġa oħra?

Mistosijiet tal-għeluq

- Innutajt il-ħin. Nistgħu nibqgħu nitkellmu sa xħin ftehemna?
- Hemm xi ħaġa li taħseb li kellna nitkellmu dwarha u għadna ma ddiskutejnihiex?
- Wara ghaddejt minn dawn l-esperjenzi, x'parir tixtieq tagħti biex jitjiebu l-affarijiet?
- Hemm xi ħaġa li tixtieq tistaqsini?
- Hemm xi ħaġa oħra tixtieq tiddiskuti jew taqsam?

Appendix 17: Interview agenda for the informal carer - English

Initial Opening Questions:

Informal Carer:

- Please tell me about what happened when your relative was hospitalised.
- What was it like? If you recall, what were you thinking then? Who, if anyone, influenced your actions? Tell me about how he/she/they influenced you?
- Could you describe the events that led up to the hospitalisation?
- What contributed to this event?
- How did the need of hospitalisation affect your decision?
- What was your life like before the admission? How did it change when your relative was hospitalised?
- Could you tell me about your thoughts and feelings when you learned that your relative will be admitted to the hospital?

Intermediate Questions/Probes

- What did you know about:
 - Coping at home?
 - Your role?
 - Appointments after discharge?
- Could you tell me about your thoughts and feelings:
 - When your relative was at the hospital?
 - When the consultant told you that your relative had been discharged?
 - Just before going home?
 - When your relative went home?
- Who, if anyone, was involved? When was that? How were they involved?
- Could you describe a typical day (yours and of your relative's):
 - Before hospitalisation?
 - At hospital?
 - Just after discharge?
- Who has been the most helpful to you during this time? How have they been beneficial?

- As you look back, are there any events that stand out in your mind? Could you describe them/it? How did the event affect what happened? How did you respond to the event/situation?
- What do you think helped you to manage this experience? What problems did you encounter? Could you tell me more?

Ending Questions

- I've noticed the time. Is it still okay to keep speaking until the time is agreed?
- Is there anything you think we should have talked about that we haven't had the opportunity to explore?
- After having these experiences, what advice would you give to improve?
- Is there anything that you would like to ask me?
- Is there anything else you would like to discuss or share?

Appendix 18: Aġenda għall-Intervista mal-pazjent - Maltese

Mistoqsijiet tal-bidu

- Jekk jogħġbok għidli x'kien għara meta dħalt l-isptar?
- Kif kienet l-esperjenza? Tiftakar x'kont qed taħseb dak il-ħin? Kien hemm xi ħadd li influwenza l-azzjonijiet tiegħek? Jekk iva, min u kif influwenzak?
- Tista' tiddeskrivi l-avvenimenti li wassluk biex tiddaħħal l-isptar?
- Liema fatturi kkontribwew għal dan l-avveniment?
- Tista' tgħidli dwar il-ħsibijiet tiegħek u x'ħassejt meta sirt taf li kienu se jzommuk l-isptar?

Mistoqsijiet intermedji

- X'kont taf fuq:
 - Kif tkampa meta tkun id-dar?
 - Ir-rwol tiegħek?
 - L-appuntamenti wara li toħroġ mill-isptar?
- Tista' tgħidli dwar il-ħsibijiet tiegħek u kif ħassejtek meta:
 - Dħalt l-isptar?
 - Il-konsulent qallek li tista' jmur id-dar?
 - Eżatt qabel ma mort id-dar?
 - Meta mort id-dar?
- Min kien involut? Meta? Kif kien/u involut/i?
- Tista' tiddeskrivi gurnata tipika
 - Qabel ma dħalt l-isptar?
 - Fl-isptar?
 - Eżatt wara li ħriġt mill-isptar?
- Min għenek l-iktar matul dan iż-żmien? Kif għenek/għenitek?
- Meta tħares lura lejn din l-esperjenza, liema avvenimenti laqtuk l-aktar? Tista' tiddiskrivihom? Kif affettwawk dawn l-avvenimenti? Kif irreaġixxajt għal dawn l-avvenimenti/sitwazzjonijiet?
- X'taħseb li għenek l-aktar f'din l-esperjenza? Liema kienu l-problemi li Itqajt magħhom? Tista' żżid xi haġa oħra?

Mistosijiet tal-għeluq

- Innutajt il-ħin. Nistgħu nibqgħu nitkellmu sa xħin ftehemna?
- Hemm xi ħaġa li taħseb li kellna nitkellmu dwarha u għadna ma ddiskutejnihiex?
- Wara għaddejt minn dawn l-esperjenzi, x'parir tixtieq tagħti biex jitjiebu l-affarijiet?
- Hemm xi ħaġa li tixtieq tistaqsini?
- Hemm xi ħaġa oħra tixtieq tiddiskuti jew taqsam?

Appendix 19: Interview agenda for the patient - English

Initial Opening Questions:

- Please tell me about what happened when you were hospitalised.
- What was it like? If you recall, what were you thinking then? Who, if anyone, influenced your actions? Tell me about how he/she/they influenced you?
- Could you describe the events that led up to the hospitalisation?
- What contributed to this event?
- Could you tell me about your thoughts and feelings when you learned that you would be admitted to the hospital?

Intermediate Questions/Probes

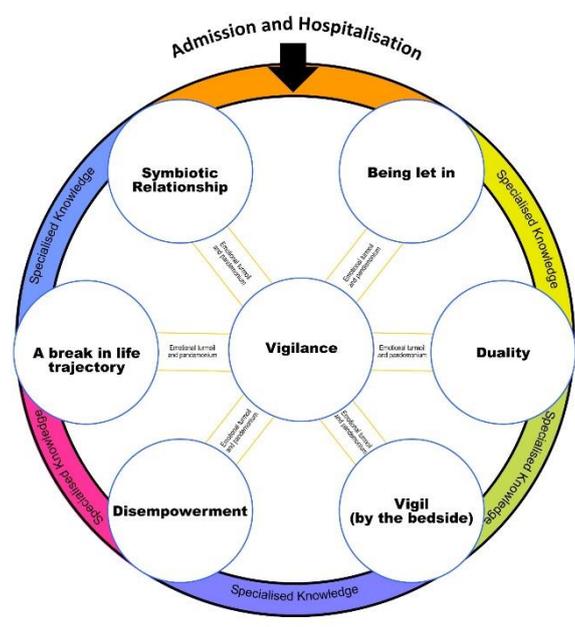
- What did you know about:
 - Coping at home?
 - Your role?
 - Appointments after discharge?
- Could you tell me about your thoughts and feelings:
 - When you were admitted to the hospital?
 - When the consultant said to you that you are discharged?
 - Just before going home?
 - When you went home?
- Who, if anyone, was involved? When was that? How were they involved?
- Could you describe a typical day:
 - Before hospitalisation?
 - At hospital?
 - Just after discharge?
- Who has been the most helpful to you during this time? How have they been helpful?
- As you look back, are there any events that stand out in your mind? Could you describe them/it? How did this event affect what happened? How did you respond to the event/situation?
- What do you think helped you to manage this experience? What problems did you encounter? Could you tell me more?

Ending Questions

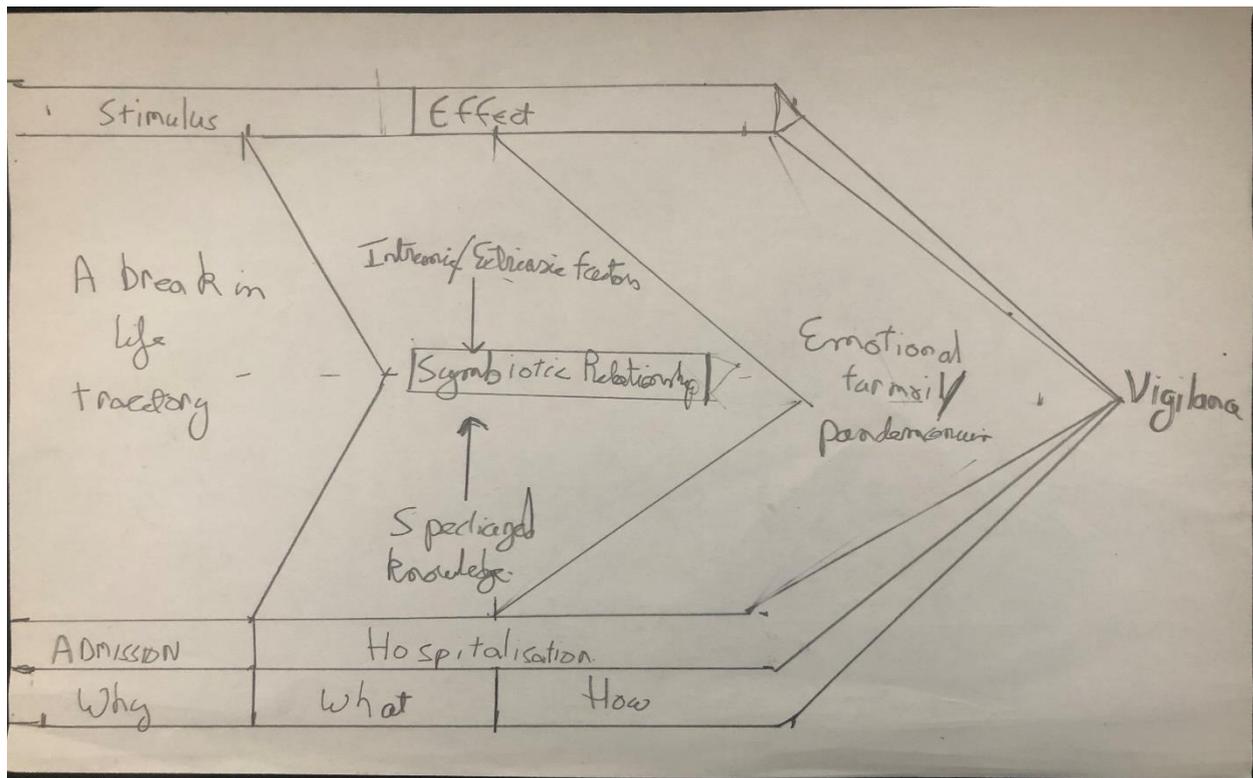
- I've noticed the time. Is it still okay to keep speaking until the time is agreed?
- Is there anything you think we should have talked about that we haven't had the opportunity to explore?
- After having these experiences, what advice would you give so things can improve?
- Is there anything that you would like to ask me?
- Is there anything else you would like to discuss or share?

Appendix 20: Theoretical memo – 25-06-2020

During the supervision meeting held on Thursday 25th July, concerns about the following model were not a process. On reflecting, the process is not straightforward yet in the below theory.



Therefore, I need to rethink and recode the above model to have a social process. The following picture is the above model in a process.



Explanation:

The informal carers on admission and hospitalisation of their relatives will change their normal lifestyle (a break-in-life trajectory). This category is affected by the notions of delaying seeking help to maintain the everyday lifestyle, the difficulties in the admission procedures, the differences between emergency admissions and elective admissions and the push from the informal carers in getting back home (discharge to go back to their normal lifestyle). The break-in-life trajectory means that the informal carers could not and are not able to take care of their relatives in their usual way due to the deterioration in the condition of their relatives. The admission and hospitalisation are seen as a stimulus for the informal carers to increase their vigilance because the patient is unstable.

To see and compare the above with stimulus and reaction theories, living with chronic disease, cultural differences (hospital vs home), locus of control.

This break-in-life trajectory (admission, hospitalisation and interruption of their everyday lifestyle) will strain the relationship between the informal carers. This relationship is based and characterised on years of knowing each other, patient relying on the informal carer, informal carer depending on the patient, supporting each other

and complementing each other. This relationship could be explained as the symbiotic one, in which both carers and the patients identify themselves as one being that benefits from each other.

To see and compare the above detachment and attachment theories, symbiosis, mutualism, teamwork/building theories, cooperation theories.

Moreover, this symbiotic relationship is influenced by extrinsic and intrinsic factors (being let in, vigil by the bedside, duality, disempowerment) based on the informal carer's specialised knowledge, increasing or decreasing informal carers' emotional turmoil/pandemonium. The intrinsic factor involves challenges that the informal carers control, preventing them from taking care of or being near the hospitalised patient. At the same time, extrinsic barriers affect challenges that the informal carer has no control over, which prevent them from taking care or being near the patient while hospitalised. Eventually, these extrinsic and intrinsic factors result in difficulty being let in, disempowerment, duality and vigil by the bedside—the informal carers experience barriers to being physically near the patients. Therefore, informal carers adapt to these barriers. At the same time, their relatives are hospitalised by negotiating, bargaining, or forcing their way to be near their relatives. These barriers include physical barriers, institutional barriers, personal commitments and knowledge barriers, whereas informal carers, when they had to leave their relatives 'alone' in the hospital or another room, are always thinking about and mentally being near the patient. Therefore, the informal carers are near their relative's bedside by proxy; physically, they are not near the patient, but spiritually, mentally and morally, they are always near their bedside. This will result from departing from the patient to waiting for the unknown to happen, living in suspense and moving towards an ambiguous future. Disempowerment is seen as the power asymmetry between informal carers and the hospital staff while relatives are hospitalised. This disempowerment will result from imposing a routine and not being recognised by the hospital staff, which will result in being submissive to having peace of mind that someone is taking care of their relatives while they are not near them. The above barriers and factors will eventually result in a duality state by the informal carers. The participants describe it as being split into two states of being. The informal carers, as a consequence of this, experience emotional duality (being strong to the patient and being anxious), role duality (being a carer and being a family

member), caring duality (being the caregiver and being the receiver of help), responsibility duality (incongruence in decision-making).

Moreover, the above barriers will have a straining effect on the symbiotic relationship between the informal carers and the patient based on years of knowing each other, taking care of each other, and specialised knowledge. Specialised knowledge is explained by how the participants' past experiences of taking care of their relatives, other relatives, repeated admissions, positive and negative past hospitalisation experiences, and years of knowing the patient resulted in informal carers acquiring skills like intuition, medical knowledge, coping mechanisms, leadership, collaboration and communication.

To see and compare the above with acceptable norms and behaviour in society, empowerment theories, emotion theories, autonomy theories, adaptation theories, Benner's novice-to-expert theory, learning theories in technical and non-technical skills.

Eventually, the notion of intrinsic and extrinsic barriers and specialised knowledge while hospitalised will strain the symbiotic relationship between the informal carer and the patient, resulting in an emotional pandemonium/turmoil. These emotions include sadness, fear, anxiety, anger, desperation, confusion, panic, grief, fatigue, tension, stress, loneliness, vulnerability, obsessively thinking, guilt, losing faith in their abilities, degrading, not being trusted etc. These emotions will trigger the informal carers in adapting to the situation by increasing their vigilance state.

Vigilance is seen as the informal carer's act of keeping careful watch for possible danger or difficulties during admission (a break-in-life trajectory) and hospitalisation (symbiotic relationship and emotional turmoil/pandemonium).

In other words – a break-in-life trajectory explains why vigilance is happening, while the influence of extrinsic and intrinsic factors and specialised knowledge on symbiotic relationships is explaining what is happening in vigilance. In contrast, the emotional turmoil/pandemonium explains how vigilance is happening.

A break-in-life trajectory and a symbiotic relationship is seen as the stimulus that could trigger the vigilance state of the informal carers. Furthermore, the strain that intrinsic and extrinsic barriers and specialised knowledge have on the symbiotic relationship is

seen as the effect of the above stimulus in the form of an emotional turmoil/pandemonium, which will result in a high vigilance state in the informal carers.

Appendix 21: Summary of Articles (Chapter 2)

Summary of the articles selected (in chronological order)			
Author, Publication Date, Country	Sample population (participants)	Study Design	Aim
Crist et al. 2006 USA	23 participants	Grounded theory – Classic	The processes by which Mexican American elders and their caregivers decide to use home care services.
Brannstorm et al. 2007 Sweden	3 participants	Phenomenological-Hermeneutic design	To illuminate the meaning of being a close relative of a person with severe CHF in palliative advanced home care.
Patel et al. 2007 Sweden	88 participants	Qualitative	To explore factors related to the patient seeking care for worsening CHF.
Luttik et al. 2007 Holland	357 participants	Cross-sectional design	To investigate determinants of caregiver burden to identify caregivers who are at risk.
Iqbal et al. 2010	179 patients	Quantitative	To assess factors affecting health-

UK	131 informal carers		related QoL in CHF patients and their carers and the impact of QoL on clinical outcomes.
Hwang et al. 2011 USA	76 participants	Cross-sectional descriptive design	To identify factors associated with the impact of caregiving.
Sanford et al. 2011 USA	20 participants	Constructivist grounded theory	To examine the process of decision-making among caregivers of patients with HF.
Yeh and Bull 2012 USA	100 participants	Descriptive, correlational research design	To examine the influence of older people's activity.
Lowson et al. 2013 UK	27 participants	Exploratory semi-structured qualitative design	To examine the meanings of family caring for the care recipients by drawing on the older adults' perspective about the impact of hospital admission on established family-caring relationships.

Kaasalinen et al. 2013 Canada	14 participants	Exploratory descriptive design	To explore the experiences of long-term care residents living and dying with heart failure, and their family members.
Bahrami et al. 2014 Iran	18 participants	Descriptive exploratory qualitative design	To explore the Iranian family caregivers' burden of caregiving for the patient with HF.
Doos et al. 2014 UK	14 participants – questionnaire 6 patients and 5 carers – in-depth interviews	Mixed method	To explore the experiences of heart failure and chronic obstructive pulmonary disease multimorbid patients and their carers on hospital discharge.
Buck et al. 2015 various	40 articles	Systematic review	To conduct a systematic review answering the following questions: what specific activities do caregivers contribute to patients' self-care in heart failure, and how mature (or

			developed) is the science of the caregiver contribution to self-care.
Fry et al. 2016 UK	11 participants	Ethnographic design	To use secondary analysis to interrogate a qualitative data set to explore the experience of patients living with heart failure.

Appendix 22: Participants' Characteristics

Harry (carer), who was 65 years old, was husband to Pamela (patient), who was 61 years old. They lived together in the central part of Malta in a townhouse. Pamela had mobility problems and was mainly wheelchair-bound. Before the interview, Pamela had been hospitalised ten times during the last six months. Her admissions were mainly due to exacerbations of CHF symptoms. Harry was retired and spent a lot of time with his wife, helping her with everyday chores. They had minimal help from friends and their children. They had been together for more than 20 years. Harry had health issues (diabetes) which sometimes prevented him from taking care of Pamela.

Patricia (patient) was an 84-year-old female who lived in the central part of Malta. She lived alone in her own home. Her main carer, Darlene (daughter and carer), lived next to Patricia. Darlene was 57 years old and was a healthcare professional. Darlene dedicated 6 hours of her time daily to her mother when she was not working. While she was at work, she coordinated her mother's care through the help of her other siblings, private carers and community nurses. Patricia was admitted twice during the last six months before the interview due to exacerbation of CHF symptoms. During the last hospitalisation, Darlene spent at least 4 to 6 hours, if work permitted, near her mum. Patricia was semi-independent and had the support of all the community services. Darlene took care of her granddaughter too, but she coordinated the care of her mother among her siblings since she was the most experienced (healthcare professional) and had taken care of her late father. Darlene's late father had suffered from CHF too.

Patrick (patient) was a 64-year-old man who lived in the south part of Malta and with Wendy (wife and carer), who was also 64 years old. They lived together in a townhouse. Patrick used an oxygen concentrator, a continuous positive airway pressure (CPAP) machine and oxygen cylinders. He had bought a portable oxygen concentrator to get out of his house since he was dependent on oxygen. Patrick still drove and tried to run some simple errands, such as shopping. He was admitted twice during the last six months before the interview due to severe shortness of breath caused by CHF. Wendy took care of her husband 24 hours a day and was a housewife. While he was hospitalised, she spent 2 to 8 hours a day, depending on the public transport, near her husband. He started to suffer from complications from a work-

related disease at a younger age (50 years) and had to stop work. They had been married for more than 40 years.

Philip (patient) was an 83-year-old man who lived in the northern part of Malta. He lived in an apartment with Whitney (wife and carer), an 80-year-old female. They dedicated a lot of time to each other. Philip used a wheelchair due to a hip fracture he had suffered in the past years. Philip and Whitney had five children, and they received a lot of support and help from them. Nevertheless, Whitney was a fully independent female and, due to her husband's condition, she preferred to stay at home with him. Philip was hospitalised once in the last six months before the interview due to hypotension and fluid overload (a CHF complication). Still, he had previously been hospitalised various times due to myocardial infarction, operations, complications, hip fracture, and other instances. Whitney spent at least 12 to 16 hours with him during hospitalisation. They had been married for more than 60 years.

Peter (patient) was an 84-year-old male, fully independent, and lived in the southern part of Malta together with Winnie, his 83-year-old wife. They had been married for 60 years. Winnie (wife and carer) was fully independent and was very active in the local community. While at home, she spent 24 hours with him, but she limited her time to 2-4 hours daily during hospitalisation. They had an excellent support system from their three children. Peter was hospitalised once in the last six months before the interview due to exacerbations of CHF.

Paula (patient) was a 77-year-old woman who lived with her husband, who was 86 years old, deaf and had dementia. They lived together in their home in the central part of Malta. She was independent but with minimal mobility because of her fragility and condition. Although she was independent, Paula was mainly housebound because of her shortness of breath. Deborah (daughter and carer) was a 42-year-old woman and healthcare professional. She did not live with Paula and had her own family with two small children. When Paula was at home, Deborah spent 1-2 hours per day near her mother, but she spent 6-8 hours near her when she was hospitalised. Deborah was helped by her sister, especially when Paula was hospitalised. Paula was admitted once during the last six months before the interview due to severe shortness of breath caused by her CHF.

Pia (patient) and Hamilton (husband and carer) are both 81 years old. They have been married for more than 55 years and lived in their own home in the central part of Malta. Pia was a semi-independent female who used walking aids to help mobility and supported community services. Hamilton, although fully independent, was housebound due to taking care of his wife. When Pia was at home, Hamilton spent 24 hours a day with her, but he spent 3-5 hours with her when Pia was hospitalised. They had a good support system from their children. Pia was hospitalised once during the last six months before the interview due to exacerbation of CHF.

Dawn (daughter and carer) was a 61-year-old female taking care of her mother (her mother did not participate in the study). She lived in the northern part of Malta next door to her mother. Dawn had been recently widowed and had no children; her husband had died from a severe brain haemorrhage during the night while he was sleeping near her. She was, however, active in the community. Dawn spent 12 hours near her mother at her last admission but had good support from her siblings. Her mother was admitted once during the six months before the interview for more than four weeks for infective exacerbation of shortness of breath and CHF.

Pam (patient) and Harley (husband and carer) were a couple who lived in the northern part of Malta. Pam was a 66-year-old female who was fully independent but primarily homebound. Harley was a 68-year-old male who was very active and still worked in his fields as a part-time farmer. They had been married for more than 40 years. Although her daughter and grandchildren lived with them, they had minimal help and support. When Pam was hospitalised, Harley visited her for 3-4 hours a day; she was admitted once in the last six months before the interview due to severe shortness of breath.

Although they were interviewed separately, Danielle (daughter) and Winter (wife) were from the same family, taking care of the same patient. Danielle was a 27-year-old female who lived with her parents and had a very active lifestyle, including being a healthcare professional. Winter was a 60-year-old female who was fully independent and had just retired from her work. Both took care of a 66-year-old male (their father and husband respectively – who did not participate in this study) who was fully independent and still active by doing a part-time job. They lived in the central part of Malta. The male has been hospitalised three times during the six months before the

interview (once for cardiac arrhythmia and twice for severe shortness of breath due to CHF). Both spent at least 3-5 hours near him when he was hospitalised. Both have good support from other members of their family.

Daphne (daughter) and Dominique (daughter) are 51 years old and 50 years old respectively and lived in the central part of Malta. Both Daphne and Dominique took care of their 77-year-old father (who did not participate in this study), who was very fragile and suffered from various conditions. Their father was semi-independent in mobility but dependent on a portable oxygen concentrator. They had to stop working to take care of their father. Before the interview, their father had ten admissions during the previous six months (due to various conditions). During the last admission, the male was hospitalised for 45 days. Daphne and Dominique spent at least 10 hours a day near their father when at home but spent nearly 24 hours near their father when hospitalised. They had excellent support from other family members, but Daphne and Dominique were the main carers.

Appendix 23: Narrative literature search (example)

Questions

How was vigilance used in literature in context of informal care of a patient during admission and hospitalisation?

How was vigilance used beyond nursing?

Aim:

- To use theoretical sampling of the literature ensuring concepts searched for have emerged from this study's data
- To use reflexivity and memoing about how search terms and selected publication are relevant to the data to prevent being leading or biased
- To situate the substantive theory within the current literature base and establish how the theory contributes to new knowledge by:
 - Comparing, compliment and discuss the central organising phenomenon and major categories with the extant literature
 - Confirming that a theory about informal care of a patient suffering from CHF during admission and hospitalisation using grounded theory methods in Malta does not exist
- To support writing of chapters 6 and 7

Keywords

(family OR families OR "informal carer*" OR "next of kin" OR Caregiver* OR "Informal caregiving" OR "informal care*")

(presence or bedside or hospital or admission or hospitalisation or hospitalization)

Vigilance

Interface - EBSCOhost Research Databases
Search **Screen** - Advanced Search
Database - Academic Search Complete; AgeLine; Cochrane Central Register of Controlled Trials; Cochrane Database of Systematic Reviews; Methodology Register; PsycINFO; MEDLINE Complete; Cochrane Clinical Answers; CINAHL Complete

S1 TX (family OR families OR "informal carer*" OR "next of kin" OR Caregiver* OR "Informal caregiving" OR "informal care*") AND TX (presence or bedside or hospital or admission or

Search **modes** - [View Results](#) (30,323)
Boolean/Phrase

hospitalisation or hospitalization)
AND TX Vigilance

Too much hits need to

S2 TI (family OR families OR "informal carer*" OR "next of kin" OR Caregiver* OR "Informal caregiving" OR "informal care*") AND TI (presence or bedside or hospital or admission or hospitalisation or hospitalization) AND TI Vigilance **Search modes - [View Results](#)** (1)
Boolean/Phrase

S4 TI (family OR families OR "informal carer*" OR "next of kin" OR Caregiver* OR "Informal caregiving" OR "informal care*") AND SU (presence or bedside or hospital or admission or hospitalisation or hospitalization) AND SU vigilance **Search modes - [View Results](#)** (2)
Boolean/Phrase

Articles already found

S6 SU (family OR families OR "informal carer*" OR "next of kin" OR Caregiver* OR "Informal caregiving" OR "informal care*") AND TI (presence or bedside or hospital or admission or hospitalisation or hospitalization) AND SU vigilance **Search modes - [View Results](#)** (1)
Boolean/Phrase **[View Details](#)**
[Edit](#)

S5 TI (family OR families OR "informal carer*" OR "next of kin" OR Caregiver* OR "Informal caregiving" OR "informal care*") AND TI (presence or bedside or hospital or admission or hospitalisation or hospitalization) AND SU vigilance **Search modes - [View Results](#)** (1)
Boolean/Phrase **[View Details](#)**
[Edit](#)

Articles already found

S7 SU (family OR families OR "informal carer*" OR "next of kin" OR Caregiver* OR "Informal caregiving" OR "informal care*") AND SU (presence or bedside or hospital or admission or hospitalisation or hospitalization) AND TI vigilance **Search modes - [View Results](#)** (11)
Boolean/Phrase

Two articles already found

Science Direct search

(family OR families OR "informal carer" OR "next of kin" OR Caregiver OR "Informal caregiving" OR "informal care") AND (presence or bedside or hospital or admission or hospitalisation or hospitalization) AND vigilance

25 hits

0 found relevant

Scopus search

(family OR families OR "informal carer*" OR "next of kin" OR Caregiver* OR "Informal caregiving" OR "informal care*") AND (presence or bedside or hospital or admission or hospitalisation or hospitalization) AND vigilance

154 hits - 45 articles chosen reading from title and abstract

Total articles found 75

Excluded articles

Addressed animals and not humans

Addressing only staff perceptions

Addressing mathematical problems

Addressing trends – infections and disease

Addressing pharmacovigilance

Addressing and evaluating a specific programm

Not hospital based

Search of theories New search 04/11/2019

("schlossberg transition theory") AND (SubjectTerms:(("informal carer" OR "family" OR "relatives" OR " partner" OR spouses))

Results 6

("schlossberg transition theory") AND ("informal carer" OR "family" OR "relatives" OR " partner" OR spouses)

Results 51

("Lewin's change theory") AND (SubjectTerms:(("informal carer" OR "family" OR "relatives" OR " partner" OR spouses))

Result 9

("Lewin's change theory") AND ("informal carer" OR "family" OR "relatives" OR " partner" OR spouses)

Results 117

Search 15/12/2019

“a break in life trajectory” open to all

Results 6

Transition query

#	Query	Limiters/Expanders	Last Run Via	Results
S4	SU transition AND SU ("Acute care" OR hospitalisation OR hospitalization OR admission OR readmission) AND SU (Caregiver OR relatives OR carer OR partner OR family OR spouses)	Expanders - equivalent Search Boolean/Phrase	Apply subjects modes - Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - AgeLine;Academic Search Complete;CINAHL Complete;Cochrane Central Register of Controlled Trials;Cochrane Clinical Answers;Cochrane Database of Systematic Reviews;Cochrane Methodology Register;MEDLINE Complete;PsycINFO;Academic Search Ultimate	72
S3	SU transition AND SU ("Acute care" OR hospitalisation OR hospitalization OR admission OR readmission) AND (Caregiver OR relatives OR carer OR partner OR family OR spouses)	Expanders - equivalent Search Boolean/Phrase	Apply subjects modes - Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - AgeLine;Academic Search Complete;CINAHL Complete;Cochrane Central Register of Controlled Trials;Cochrane Clinical Answers;Cochrane Database of Systematic Reviews;Cochrane Methodology Register;MEDLINE Complete;PsycINFO;Academic Search Ultimate	207
S2	SU transition AND ("Acute care" OR hospitalisation OR hospitalization OR admission OR readmission) AND (Caregiver OR relatives OR carer OR partner OR family OR spouses)	Expanders - equivalent Search Boolean/Phrase	Apply subjects modes - Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - AgeLine;Academic Search Complete;CINAHL Complete;Cochrane Central Register of Controlled Trials;Cochrane Clinical Answers;Cochrane Database of Systematic Reviews;Cochrane Methodology Register;MEDLINE Complete;PsycINFO;Academic Search Ultimate	490
S1	transition AND ("Acute care" OR hospitalisation OR hospitalization OR admission OR	Expanders - equivalent Search Boolean/Phrase	Apply subjects modes - Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - AgeLine;Academic	4,620

readmission) AND (Caregiver OR relatives OR carer OR partner OR family OR spouses)

Search Complete;CINAHL Complete;Cochrane Central Register of Controlled Trials;Cochrane Clinical Answers;Cochrane Database of Systematic Reviews;Cochrane Methodology Register;MEDLINE Complete;PsycINFO;Academic Search Ultimate

Status quo query

#	Query	Limiters/Expanders	Last Run Via	Results
S3	TI "status quo" AND SU (Caregiver OR relatives OR carer OR partner OR family OR spouses)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - AgeLine;Academic Search Complete;CINAHL Complete;Cochrane Central Register of Controlled Trials;Cochrane Clinical Answers;Cochrane Database of Systematic Reviews;Cochrane Methodology Register;E-Journals;GreenFILE;MEDLINE Complete;PsycINFO;Zoological Record;Academic Search Ultimate	68
S2	SU "status quo" AND SU (Caregiver OR relatives OR carer OR partner OR family OR spouses)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - AgeLine;Academic Search Complete;CINAHL Complete;Cochrane Central Register of Controlled Trials;Cochrane Clinical Answers;Cochrane Database of Systematic Reviews;Cochrane Methodology Register;E-Journals;GreenFILE;MEDLINE Complete;PsycINFO;Zoological Record;Academic Search Ultimate	4
S1	"status quo" AND (Caregiver OR relatives	Expanders - Apply equivalent subjects	Interface - EBSCOhost Research Databases	3,650

OR carer OR partner Search modes - Search Screen - Advanced
 OR family OR spouses Boolean/Phrase Search Database - AgeLine;Academic
) Search Complete;CINAHL
 Complete;Cochrane Central
 Register of Controlled
 Trials;Cochrane Clinical
 Answers;Cochrane Database
 of Systematic
 Reviews;Cochrane
 Methodology Register;E-
 Journals;GreenFILE;MEDLINE
 Complete;PsycINFO;Zoological
 Record;Academic Search
 Ultimate

5 articles

#	Query	Limiters/Expanders	Last Run Via	Results
S2	"status quo" AND ("heart failure" OR HF OR CHF OR "congestive heart failure" OR "cardiac failure")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - AgeLine;Academic Search Complete;CINAHL Complete;Cochrane Central Register of Controlled Trials;Cochrane Clinical Answers;Cochrane Database of Systematic Reviews;Cochrane Methodology Register;E- Journals;MEDLINE Complete;PsycINFO;Academic Search Ultimate	47
S1	"status quo"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - AgeLine;Academic Search Complete;CINAHL Complete;Cochrane Central Register of Controlled Trials;Cochrane Clinical Answers;Cochrane Database of Systematic Reviews;Cochrane Methodology Register;E- Journals;MEDLINE Complete;PsycINFO;Academic Search Ultimate	36,663

One article

Symbiotic relationship query

#	Query	Limiters/Expanders	Last Run Via	Results
S5	SU "symbiotic relationship" AND (Caregiver OR relatives OR carer OR partner OR family OR spouses)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - AgeLine;Academic Search Complete;CINAHL Complete;Cochrane Central Register of Controlled Trials;Cochrane Clinical Answers;Cochrane Database of Systematic Reviews;Cochrane Methodology Register;GreenFILE;MEDLINE Complete;PsycINFO;Academic Search Ultimate	12
S4	SU "symbiotic relationship" AND SU (Caregiver OR relatives OR carer OR partner OR family OR spouses)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - AgeLine;Academic Search Complete;CINAHL Complete;Cochrane Central Register of Controlled Trials;Cochrane Clinical Answers;Cochrane Database of Systematic Reviews;Cochrane Methodology Register;GreenFILE;MEDLINE Complete;PsycINFO;Academic Search Ultimate	3
S3	"symbiotic relationship" AND SU (Caregiver OR relatives OR carer OR partner OR family OR spouses)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - AgeLine;Academic Search Complete;CINAHL Complete;Cochrane Central Register of Controlled Trials;Cochrane Clinical Answers;Cochrane Database of Systematic Reviews;Cochrane Methodology Register;GreenFILE;MEDLINE Complete;PsycINFO;Academic Search Ultimate	194
S2	"symbiotic relationship" AND (Caregiver OR relatives OR carer OR partner OR family OR spouses)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - AgeLine;Academic Search Complete;CINAHL Complete;Cochrane Central Register of Controlled Trials;Cochrane Clinical Answers;Cochrane Database of Systematic Reviews;Cochrane Methodology Register;GreenFILE;MEDLINE Complete;PsycINFO;Academic Search Ultimate	5,363
S1	"symbiotic relationship"	Expanders - Apply equivalent subjects	Interface - EBSCOhost Research Databases	19

AND ("heart failure" OR HF OR CHF OR "congestive heart failure" OR "cardiac failure")
 Search modes - Boolean/Phrase
 Search Screen - Advanced Search Database - AgeLine;Academic Search Complete;CINAHL Complete;Cochrane Central Register of Controlled Trials;Cochrane Clinical Answers;Cochrane Database of Systematic Reviews;Cochrane Methodology Register;GreenFILE;MEDLINE Complete;PsycINFO;Academic Search Ultimate

3 articles

(symbiosis OR symbiotic) AND (SubjectTerms:((Caregiver OR relatives OR carer OR partner OR family OR spouses))) in Brighton university using social sciences and nursing databases

161 hits

Maslow

Maslow hierarchy of needs and Caregiver OR relatives OR carer OR partner OR family OR spouses

50 articles

Resilience

Caregiver OR relatives OR carer OR partner OR family OR spouses AND resilience – open test – over 42 K

Caregiver OR relatives OR carer OR partner OR family OR spouses And resilience – subject terms – over 4K

Caregiver OR relatives OR carer OR partner OR family OR spouses And resilience – subject terms – in nursing and social sciences data data bases - 410 hits

Caregiver OR relatives OR carer OR partner OR family OR spouses And resilience – title – in nursing and social sciences data data bases - 140 hits – to check

Caregiver OR relatives OR carer OR partner OR family OR spouses And resilience AND “Acute care” OR hospitalisation OR hospitalization OR admission OR readmission

- All subject terms – in nursing and social sciences data bases

8 hits – 5 articles chosen

(resilience) AND (SubjectTerms:((Caregiver OR relatives OR carer OR partner OR family OR spouses))) AND (SubjectTerms:(“Acute care” OR hospitalisation OR hospitalization OR admission OR readmission)) in nursing and social science databases

54 hits – 14 articles chosen

Caregiver OR relatives OR carer OR partner OR family OR spouses And resilience AND “Acute care” OR hospitalisation OR hospitalization OR admission OR readmission

– subject terms the first two open the last word – in nursing and social sciences data data bases - 88 hits – 22 articles chosen

Eliminating the doubles – 24 articles chosen to read

Appendix 24: Example of re-focusing coding from initial coding

Quotes	Initial codes	Focus code	Memo
<p>Quote 1</p> <p>Deborah (daughter and carer): You need to understand that I was worried, even though I was a bit lucky because in the morning I could be near her in the ward (the carer is a healthcare professional), and my colleagues were very understanding and used to encourage me to go near her. And in the afternoon, I knew that my sister would go near her, but I would worry during the night. The night is too long. I was concerned because my sister would leave at about 8 pm, and no one would take a look at her until 8 am the following morning. It is true that she was in the hospital, but because she had MRSA, they (the healthcare professionals) used to go near her just to give her the treatment, that's it. She is too shy to use the buzzer. And I used to say if something happened to her, no one would notice. So, I used to worry a lot, and during the night I used to go near her till about 1 am or 2 am and I used to say the night is shorter like this because I couldn't sleep at home</p>	<p>Presence</p> <p>Watchful waiting</p> <p>Constant watchfulness</p> <p>Loss of control</p> <p>Caring</p> <p>Harm avoidance</p> <p>Caring</p> <p>Constant watchfulness</p>	<p>Vigilance</p>	<p>The word vigilance could explain what is happening in these six quotes in a single word. This is because the informal carer show how their presence could help their relative avoid harm. The informal carers acknowledge that the only way to help or prevent harm to their relatives in these instances of admission and hospitalisation is by</p>

<p>thinking about her. I used to feel better near her because at least I could see her with my own eyes, you know.</p> <p>Quote 2 Deborah (daughter and carer): After the cardiac ward, she was transferred to another ward. It's a really good ward, and I praise them for the work they do. But in a way, there is a drawback being in a single room, because if she was in a four-bedded or six-bedded area and something happened to her, one of the other patients would notice and call the nurses – that what was my main worry: that she was alone, even though she was comfortable. Even we were comfortable because we could go and see her and stay near her more easily, I used to worry that something could happen to her and no one would notice it.</p>	<p>caring</p> <p>Duty</p> <p>Caring</p> <p>Lack of control</p> <p>Loss of dignity</p>	<p>Vigilance</p>	<p>being there and increasing their constant watchfulness. This showed their duty as an informal carer but even their care. However, they expressed their vulnerability by showing a lot of emotions such as anxiety.</p>
<p>Quote 3 Deborah (daughter and carer): My sister and I were really stressed during that period.</p>	<p>Vulnerability</p> <p>Constant watchfulness</p> <p>Watchful waiting</p>	<p>Vigilance</p>	

<p>Quote 4</p> <p>Darlene (daughter and carer): Whenever she is in an acute phase, I am really anxious because I think that she [her mother] is going to die... because you feel really hopeless and you have to thank them [hospital staff] even though you feel hopeless... here at home I have everything under control, while there [at the hospital] you lose everything because there [hospital] you have nothing, there you are in their hands [hospital staff] that's it</p>	<p>Loss of dignity Constant watchfulness Lack of control Watchful waiting Invisibility Harm avoidance Harm avoidance</p>	<p>Vigilance</p>	
<p>Quote 5</p> <p>Winter (wife and carer): When they (hospital staff) tell you that he [her husband] has something wrong in his heart, I was shocked because I never expected it. When he was admitted I used to be near him all the time because he would constantly be on your mind, and you would constantly be thinking, 'What is happening? What is going to happen?' You wouldn't know what might happen and you wait...</p>	<p>Vulnerability Presence Constant watchfulness Lack of control</p>	<p>Vigilance</p>	

<p>Quote 6</p> <p>Darlene (daughter): It is scary, you know, and we've been through this several times, but I don't want her to put on a nappy, and we always try to resist. So, we [Darlene's siblings] go there very early in the morning and take turns to be near her all, but not during the night because everyone has to rest a bit. But we leave her alone the least time possible, and then we will go again as early as possible in the morning, so, if possible, we help her go to the toilet and avoid the nappy. She can take lactulose and supps to help her; these are basic things. She is 84, and she never had a nappy, and absolutely we do not want her to wear a nappy.</p>	<p>Duty</p> <p>Caring</p> <p>Loss of dignity</p> <p>Vulnerability</p> <p>Presence</p> <p>Watchful waiting</p>	<p>Vigilance</p>	
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