The Cancer Patient's Lived Experience of the Health System in Malta

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A dissertation submitted in partial fulfilment of the requirements for the Master of Science in Health Services Management

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“Cancer begins and ends with people. In the midst of scientific abstraction, it is sometimes possible to forget this one basic fact … Doctors treat diseases, but they also treat people, and this precondition of their professional existence pulls them in two directions at once.”

June Goodfield

L-Università ta' Malta

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To the significant persons in my life,

particularly my father and mother,

who taught me to raise a voice for service users!

Abstract

This qualitative study explores the experiences of cancer patients and their support networks during their treatment. Within the context of public health services in Malta, it investigated the research question: How do cancer patients, their families and significant others live their experience as health service users during the illness? The Donabedian approach to service evaluation, encompassing structure, process and outcome, served as a guiding theoretical framework.

Six patients and their significant others accepted an invitation by their medical consultant to be interviewed in-depth. Their detailed narratives were analysed using Interpretative Phenomenological Analysis (IPA). Five superordinate themes emerged: positive treatment experience; overcoming identified service limitations; humanity of care; centrality of support, and burden of treatment. IPA's thorough idiographic approach captured the unique understanding through which each participant interpreted the cancer treatment reality.

Participants expressed a generally positive experience of the health services, albeit identifying limitations needing ongoing improvement efforts that respond to their needs. Humane care was deemed indispensable, particularly at communication of diagnosis. Support, both familial and work related, were considered central to the management of their treatment. The burden of treatment experienced accentuates the criticality of cancer treatment structures and processes that respond to each patient's unique experience to render the burden more manageable. A major weakness elicited from this study is the absence of structures and processes, including palliative care protocols, that respond to the particular needs of these patients upon admission to the acute care hospital.

Notwithstanding the limitations around the small size of this study, the IPA design provided a means for integrating user input into health policy and services design and evaluation. It highlighted the importance of recognising the individuality of cancer treatment experiences, and the necessity that such experiences inform treatment policies and protocols to better serve the distinctiveness of each cancer treatment journey.

Key words: living with cancer; cancer treatment experience; burden of treatment; full-time patients; humanity of care.

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Table of Contents

List of Tables

List of Figures

Abbreviations and Acronyms

A&E	Admissions and Emergency Department, MDH
ENT	Ear, Nose and Throat Department, MDH
Hem-CAB	Haematology Community Advisory Board
IPA	Interpretative Phenomenological Analysis
MDM	Minimally Disruptive Medicine Theory
MDH	Mater Dei Hospital
MH	Ministry for Health, Malta
MHECC	Ministry for Health, the Elderly and Community Care, Malta
MNCR	Malta National Cancer Registry
OC	Sir Anthony Mamo Oncology Centre
OP	Outpatients Department at MDH
PREMs	Patient Reported Experience Measures
PROMs	Patient Reported Outcome Measures
PSSM	Patient Satisfaction Strategy Map
USA	United States of America
WECAN	Workgroup of European Cancer Patient Advocacy Networks
WHO	World Health Organisation

Chapter One: Introduction

1.1 The Cancer Experience

Cancer is a major cause of morbidity and mortality in the Maltese Islands, with almost 30% of all deaths, around 990 deaths annually, attributed to cancer (Ministry for Health [MFH], 2017). Over 9.6 million people worldwide are estimated to have died from cancer in 2018 (World Health Organisation [WHO], 2018). In 2018 in Europe alone there were 3.8 million projected new cases of cancer and 1.9 million deaths, with the most common cancer sites being breast cancer, followed by colorectal, lung and prostate cancer (Ferlay et al., 2018). Such high incidence rates inevitably place cancer as a priority in any health system policy agenda, and both cancer treatment and cancer survivorship are an integral part of the EU research agenda (Lagergre et al., 2019). In addition to its immense economic cost (WHO, 2018), the impact of cancer is biopsychosocial in nature, affecting all dimensions of one's life and one's circles of support.

1.2 The Genesis of Cancer

Cancer is considered a modern illness. In the history of medicine there are no specific words for cancer, nor a goddess for cancer. Mukherjee (2010) argues that this void ensues because cancer is an age-related disease, and prior to our modern age, personhood had a short life expectancy. People died from other illnesses prior to potentially dying of cancer, such as cholera or the plague.

Longevity is also a major factor in the frequency of the diagnosis of cancer (Mukherjee).

1.3 The Epidemiological Situation in Malta

In 2014, 1045 new cases of cancer were reported in Malta, a 58% increase over a ten-year period (Malta National Cancer Registry [MNCR], 2016). The annual cancer incidence is approximately 2000 persons while the annual mortality rate caused by cancer related illnesses is reaching a 29% of all deaths (MH, 2017).

King George V hospital in Floriana, Malta, built under British rule, was in 1970 refurbished and renamed Sir Paul Boffa Hospital and reorganised to cater for infectious disease, dermatology and cancer cases. This Hospital officially launched oncology services on our island at a time were the incidence of cancer started increasing (Savona Ventura, n.d.). Since its inception, the oncology sector in Malta has undergone significant investment and transformation.

The first National Cancer Plan for Malta in 2011 instituted a holistic approach to cancer, from prevention through to screening, diagnosis, treatment, support and research (Ministry of Health, Elderly and Community Care [MHECC], 2011). Recognising that survival rates for certain cancers had improved, the National Plan defined the challenge of being a cancer survivor as implicating more than "not succumbing to the fatal illness … it also means coping with the aftermath of the illness and continuing with one's life to the best of one's ability" (MHECC, p. 11).

Proposals for a significant upgrade in the provision of cancer services were also included in this first National Cancer Plan, leading to a new Oncology Centre

(OC) steered towards being a centre of excellence in the delivery of oncology services, and built as an annex to Malta's General Public Hospital, Mater Dei Hospital (MDH). The migration of all paediatric and adult cancer and haematology services to the new OC in September 2015 brought together the oncology services previously offered from different locations.

In 2017, the second National Cancer Plan for the years 2017-2021 was published, declaring as its main key element the implementation of measures to ensure the continuum of care for the cancer patient's journey (MH, 2017). There is no specific mention of the service users' perspective in this plan. This dearth of the service user' experience can be partially addressed if patients are given the opportunity to share their experience of the health services in the context of living with their cancer. This study aims to address the gap in knowledge on the perspective of cancer service users.

1.4 Conceptual Framework

Donabedian's approach to health services evaluation incorporates the dimensions of structure, process and outcome (Donabedian, Wheeler & Wyszewianski, 1982; Ibn El Haj, Lamrini, & Rais, 2013). The structure comprises all the factors that affect the context in which care is delivered, whereas the process is the sum of all actions that shape the health services, including actions produced by the patient and significant others. The structure and the process steer outcomes affecting patients' populations, be it patient satisfaction or health correlated outcomes and quality of life. This research project explores the impact that health services have on a patient's quality of life, in its complexity and diversity, as seen from the reality of the patient and carer perspective. People's

experiences can shed light on the way health services are being offered by understanding how they are received. Moreover, health systems are enabling mechanisms whose ultimate success depends on their ability to be person centred (Donabedian, 1987; Donabedian, as cited in Mullan, 2001, p. 140).

As a result of new treatment options, cancer is increasingly becoming a chronic illness with improving survival rates. This reality, however, provides new challenges to living with cancer (MH, 2017). Patients are required to visit hospital more frequently, thus experiencing more disruptions in their weekly routines. How does one manage to fit blood tests, imaging, and liaising between different sections of the health care system etc. and still carry on with one's life? All interaction between patient and health services has a significant impact on the patient's life beyond being a cancer patient, and a consequential impact on significant others in the patient's life (Wagstaff & McIntyre, 2017). This study provides a lens on aspects of service delivery that are often overlooked.

1.5 Aims of this Research

The aims of this study are twofold:

1. To describe and critically appraise the experience of cancer patients and their significant others as they go through the process of receiving care for cancer; and
2. To analyse the factors in the delivery of health services that directly impact the life of a cancer patient, the patient's family and support system.

1.6 Research Purpose

This study aims to contribute to the understanding of what it means to become a cancer patient: receiving the cancer diagnosis, adapting one's life to attend medical appointments, undergo operations, treatment, monitoring, as well as coping with the practical day-to-day variations a cancer treatment experience brings. Within the Maltese context, such a study aimed to provide information regarding the contribution being made by the oncology service from the perspective of the consumers of the service.

Considering the above, the research question guiding this study was the following: **How do cancer patients, their families and significant others live their experience as health service users during the illness?**

1.7 Theoretical Underpinnings of this Study

The structure for this study draws upon several theoretical frameworks with the common starting point being that humans are social animals and live in families, relationships, communities. Therefore, a systems' theory perspective underpins the study.

1.7.1 Family systems

Family systems is a theory of human behaviour analysing families as emotional units where a systematic thinking framework is used to exemplify the complex interactions of such a unit. Psychiatrist Dr. Murray Bowen (1960) used systems thinking to illustrate human behaviour connectedness and reactivity within the family unit, emotionally affecting reciprocal changes in the functioning of each other, and in social systems. It was argued that comprehending "how the

emotional system operates in one's family, work, and social systems reveals new and more effective options for solving problems" (Kerr. 2000, p. 2). Systemic theory has contributed to the understanding that individuals do not experience illnesses in isolation of the rest of their life and the system within which their life functions. Applying such theoretical approach to this study allows the research to contextualise and conceptualise the experience of cancer and cancer treatment within the patient's family/society/health services' complex system (Stanton, 2009).

1.7.2 Systemic Approach

The concepts of Family Systems Theory also apply to non-family groups, such as social institutions and hospitals, and the systemic approach to conceptualising health services is core to Donabedian's seminal and extensive work on quality in health services. Health systems research and administration require a holistic conceptual framework (Donabedian, as cited in Schiff & Rucker, 2001). What came to be known as the Donabedian model established seven pillars of care assurance in health management within the structure-process-outcome framework (Donabedian, 1980; Donabedian, 1990). The patient-services interaction process takes place within different physical environments or structures, leading to outcomes reflecting intended improved patient wellbeing. Within Donabedian's seven pillar structure of quality, the notion of "acceptability" focuses on health systems' ability to respond to the patient's preferences to health care in all its dimensions (Donabedian, 1990) including the "wishes, desires, and expectations of patients and responsible members of their family" (Donabedian, 2003, p.18). This understanding places the patient's preferences

as central to a systemic approach to achieving quality in health care services outcomes.

Donabedian's theoretical framework sets all aspects of a health care system as interdependent. Donabedian argued for a consensus towards a common purpose among the primary organisational setups in health organisations with a key role for service users. He spoke of patients as consumers playing a variety of roles in quality, assessment and monitoring with consumers' preferences becoming "the paramount consideration in defining the quality of the interpersonal process and of the amenities of care" (Donabedian, 1987, p. 81).

1.7.3 The holistic care model

The systemic approach to understanding illness and its treatment underscores the need for a health care model that moves beyond a narrow medical treatment of illness. Oliviere (2001) affirms a holistic care model with pain displaying itself through body, mind and spirit which are "housed in a context: of family, neighbourhood, community and society, essentially within social relationships" (p. 238). Relationships play a crucial role, with Oliviere claiming that the quality of social life can be measured by our social relationships. Patients fall in the centre of circular interfaces of intimacy, friendship, participation and economic exchange (Snow, 1998; Davis, 2005), involving family, friends, informal carers, volunteers, bureaucrats and their medical team, possibly also including social workers, therapists, chaplains and other professionals who operate beyond the formal care structure. In the wider network, the public systems of hospitals, social care, social security, education and employment, both condition and are conditioned by the patient's more intimate circles of support. Oliviere sees a

flexible, well-functioning multi-professional team with such team members, at different times, working globally, with any or all, of the aspects such systems impinge upon.

1.7.4 The medical model and person-centred care

Within the traditional medical model of care the patient is told what to do; the patient has little say in his or her treatment and the doctors know best. Such model is a hierarchical model with physicians as the sole experts steering the patients along the hospital system, possibly with a streak of paternalism which, in the area of health, generally has a shielding intent. This approach maintains a clear boundary between the consultant and the patient who is viewed as 'multiple distinct ailments', a set of problems. In contrast there is 'patient centred care' and, more recently, the 'person centred care'. Person centred care treats the person, not the disease, in a holistic way; the patient's expertise in one's own life is paramount in the treatment decision process, with healing depending upon the therapeutic relationship between health professionals and the patient. Person centred care is relationship focused, with the patient seen as human, with a multitude of needs and wishes, not all solved medically. This concept resonated in Concordance, a partnership of equals rooting from the WHO which, in its Ottawa 1986 Convention, established the right of every person to participate in his or her own health care (McKinnon, 2014). It can be argued that the full participation in one's own care places the service user as co-producer in the structure-process-outcome framework (Donabedian, 1988b).

1.8 Expected Implications and Contributions to Knowledge

A focus on the experience of being a cancer patient, an examination of this lived experience, an understanding and interpretation of the impact health services have on the lives of its service users and their families and their supports, can contribute to knowledge essential to 'refashion our institutions' that will transform the possibilities for patients to live through their treatment and care journey.

It is expected that this study's insights into the meaning patients give to their treatment story contribute to the knowledge base health services draw upon in their planning, design, management and operations. Such knowledge can inform and support the improvements necessary for health services in Malta to become more in line with patients' lived experiences, giving patients space to function as co-producers of their own care.

1.9 Conclusion

Cancer occupies a pivotal space at all levels of health care policy, planning, and service delivery. As progress in health services contributes to increase in longevity, the prevalence of cancer intensifies and the likelihood that one experiences cancer rises. Advancement in the health services response to cancer necessarily involves the recognition of how cancer patients and their support networks experience the health services and the contribution of such an experience to sustain them through the treatment journey. The health services for cancer patients and the way they interrelate with the service users becomes a central theme constituent of the cancer experience.

The following chapter presents a review of published literature on the lived experiences of cancer patients. Chapter three describes the methodological approach to this study. Chapter four presents the key findings from the interviews together with the interpretation of the findings and discussion in relation to the literature. In the final chapter the salient research findings are critiqued bearing in mind the strengths and limitations of the study. Conclusions and recommendations emanating from the study are presented.

Chapter Two: Literature Review

2.1 Introduction

At the beginning of the 20th century diagnosing an individual with cancer was difficult. Numerous deaths of patients suspected of having died of cancer were never declared so (Mukherjee, 2010). Little was known about the aetiology of cancer and cancer was feared as a contagious disease. With fear came stigmatisation (Sontag, 2001). Most patients experienced excruciating physical pain, complicated by the terrible stigma of fast deteriorating mutilated bodies with foul-smelling tumours due to lack of hygiene. The discovery of anaesthesia brought a relief and a transformation to cancer diagnosis whereby surgeries could be carried out in a pain-controlled set-up, lending a curative chance further boosted in the 1920's with the introduction of radiation. With this 'hierarchy of needs' shift from basic pain management being made possible, the notion of patient support and emotive care slowly filtered the medicine world of cancer (Gehlert & Browne, 2006).

Parson's (1951) sick role model, emphasising the rights and obligations arising from illness, closely described the patient-doctor relationship generally adopted in hospitals and health personnel. According to Parson, illness trusts the person in the sick role, implying an exemption from normal work, family and social role obligations; yet, the patient is subject to seek medical treatment and to comply with doctors' orders. The sick role model bypasses the patient's experience of being ill, making the actions and behaviours of the medical professional supreme. Although Parson's sick role model no longer explains the changing patient-doctor

relationship, it emphasised the illness-health-medicine institutional set up within a wider understanding of how society works (Frank, 2012). Increasingly, the new generations of patients are pushing the boundary of health to person care, with individuals in health systems charting their own treatment and care, far from the subordinate role of the sick model. Donabedian (1992) argued for patients as contributors to, and targets of, quality assurance in health care, but also as reformers of health care services.

2.2 Literature Review Strategy

This section describes the sequential search strategy that guided the literature review.

Psych INFO, Cochrane Database of Systematic Review, Medline and Google Scholar were the search engines used for this review. The Google Scholar search facility was used to commence the search, inputting the following key phrases in the Google Scholar search engine: “life of cancer patients”, resulting in over 5,000 results from the time period 2013 to 2018. Additionally, using the phrase “health system impedes or assists the life of adult cancer patients” yielded about 17,000 results from 2016. “normality in the life of adult cancer patients” resulted in 16,000 articles from the year 2016 to 2018.

Such initial searches led to the refinement of the search strategy with selection of key words which were then used for the systematic search carried out on the topic. The selected key words and phrases were: “cancer patient*”, “quality of life”, “burden of treatment”, “health services”, “support”, “caregiver burden”, “full time patient”, “frequent appointments in health”, “normality in life of adult cancer patients”.

A search via EBSCO, Psych INFO, Cochrane Database of Systematic Review and Medline using the key search terms “cancer patient*” AND “quality of life” AND “health services” yielded 55 articles.

The search via Google Scholar search engine combining the following search terms: “cancer patients”, “quality of life”, “health services”, “burden of treatment” and “support” identified 40 articles for the years 2016 to January 2018. The abstracts of these 40 articles were reviewed to identify those articles that focused exclusively on cancer patients’ and care givers’ experience of treatment and the impact of the treatment on their quality of life, both during and after the treatment.

As the work evolved further searches were carried out. Another search via EBSCO with the key words “cancer” AND “burden of treatment” AND “patient*” resulted in 25 articles.

A further search also via EBSCO search engine with the combined key words of “cancer patient*” AND “caregiver burden” AND “support” for the years 2014 to January 2018 resulted in 30 articles.

The above totalled 150 articles selected, out of which 53 articles were selected for further review (18 out of 55; 13 out of 40; 9 out of 25; and 13 out of 30).

2.2.1 Inclusion and exclusion criteria

Reference lists of the 53 articles chosen for further review were manually screened for any additional relevant studies. Articles were further appraised to select the list of articles that were then reviewed in greater depth.

The selection criteria included articles that were written in the English language chosen from both qualitative and quantitative studies, with preference for the most recently published articles.

The following exclusion criteria was used in the final selection of articles for this review:

- Topic specific articles, such as particular treatment regime studies;
- Studies that focused exclusively on one sub-type of cancer in relation to health services;
- Studies carried out in a specific community that was not related to the Maltese context, such as rural communities in developing countries;
- Articles that focused exclusively and narrowly on nursing aspects of cancer services;
- Studies pertaining to paediatric oncology since the focus of this study was cancer patients.

Following a detailed examination of the 53 articles using the exclusion and inclusion criteria set above, 23 articles were selected for further review (See Fig 1, p. 15). The selected articles were still wide-ranging, from different authors and from a variety of countries, including what can be considered culturally distinct countries.

2.2.2 Further search related to topics arising from interviews

Further to the above systematic review, following the data collection, topics were identified that steered the researcher to a supplementary review. Additional key words and phrases searched via Google Scholar were “humanity AND cancer

care"; "health confidence" was searched linked to the concept of "health literacy"; with "co-production" also searched. "consumer advocacy groups" and "patients voice" were searched, as well as "psychosocial care in cancer patients". The concept of "patients voice" led to related research literature on "outcome measures and creativity" from the managerial aspect of health services.

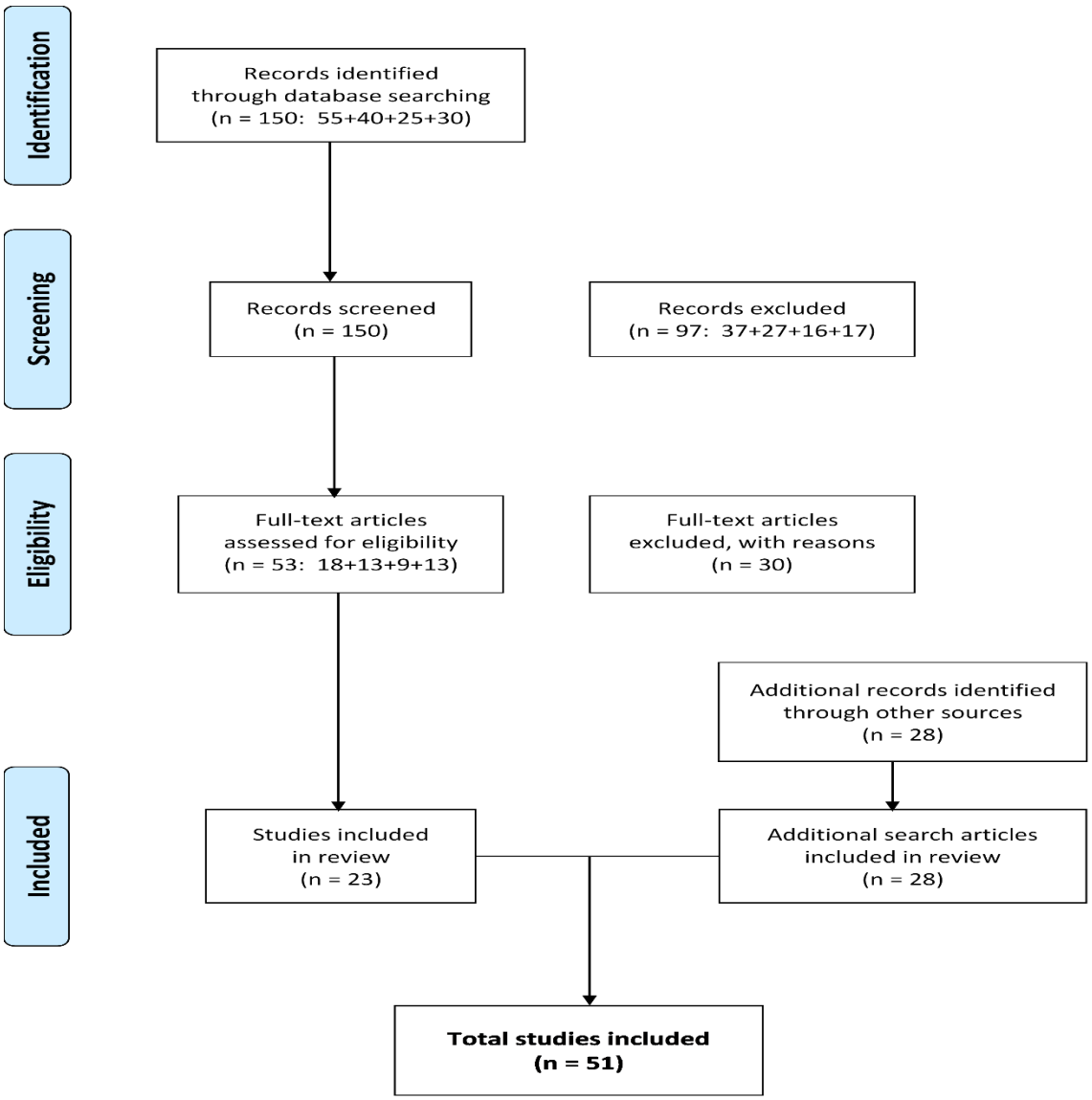

Figure 1: The PRISMA flow diagram (Moher, Liberati, Tetzlaff & Altman, 2009).

Twenty-eight articles were selected, reviewed and integrated in the literature strategy. This supplementary search used the same exclusion and inclusion criteria for the initial articles' selection process. Such search was sequential in nature with an iterative process where the richness of the data gathering prompted further reading and analysis (Creswell, 2009).

A total of 51 articles were reviewed and included in this study's literature appraisal, in addition to other studies that informed the theoretical framework of the research. The formal literature search results are presented in Fig 1 (on page 15).

In summary, while the literature review commenced as a systematic review, it evolved as an iterative process. With a thematic method like Interpretative Phenomenological Analysis (IPA) allowing for a high degree of iteration to occur in analysis, the literature review incorporated additional searches on topics related to the research question as highlighted in participants' stories (Barnett-Page & Thomas, 2009).

2.3 Definitions

The terms 'service user', 'client' and 'patient' are used interchangeably in this study. That is not to say that every client is a patient. However, in the context of a hospital, the 'patient' is a 'client' of the health service and a 'user' of that service. Although this study's focus is the 'person', it also acknowledges that during the lengthy cancer treatment journey the individual dons a patient's 'attire', not out of choice, but forced by the effects of the challenging illness-recovery roller-coaster (May, Montori & Mair, 2009; Swash, Bramwell & Hulbert-Williams, 2017; Wagstaff & McIntyre, 2017).

The contemporary term ’cancer survivor’ is also used. This term refers to a wide range of cancer patients, from those commencing treatment to those post first, or more, treatment periods (Abu, Gallacher, Boehmer, Hargraves, & Mair, 2015). In this study, it is used with reference to those having surpassed the first intensive cancer treatment of chemotherapy, or combined chemotherapy with radiotherapy, and are living beyond their side effects. Being a cancer survivor “does not only mean not succumbing to the fatal illness, rather, it also means coping with the aftermath of the illness and continuing with one’s life to the best of one’s ability” (MHECC, 2011, p. 11).

A ‘palliative patient’ is another term used in this study. The WHO defines Palliative Care as:

> An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO, n.d.).

2.4 Cancer Survivors

With advancement in cancer treatment the term ’survivorship’ is frequently being used in the cancer sphere. Twelve million Americans are estimated to be cancer survivors, one fourth of whom having survived for more than 30 years since diagnosis (Nightingale et al., 2011). Three per cent of Malta’s population are cancer survivors diagnosed since 1994 (MNCR, 2016). These prevalence rates highlight the importance of focusing on life beyond the treatment phase, which also depends significantly on how one copes with the treatment burden. Consequently, the impact of health services is carried well beyond the acute

treatment phase. The relentless increase in cancer survivorship increases the importance of recognising the long-term impact of treatment burden from the survivors' perspectives (Abu et al., 2015).

In the delivery of care to patients with multiple, long term health conditions the Minimally Disruptive Medicine Theory (MDM) is being developed. The MDM is a patient centred approach focused on patients' life and health goals (May et al., 2009). It is a statement of care for the whole person, incorporating the individual and the patient. It is also an acknowledgement of caregivers' input in patients' healthcare demands. In MDM professionals are tasked to work with patients and caregivers to come up with the least disruptive care that "advances patient goals with the smallest possible healthcare footprint on their lives" (Leppin, Montori & Gionfriddo, 2015, p. 51). MDM is considered to be specifically suitable for patients "at risk of being (or who already are) overwhelmed by the demands of life, illness, and health care … MDM seeks to rightsize and redirect care strategies to fit patient context and be minimally disruptive and maximally supportive" (Leppin et al., p. 51).

These care strategies emphasise the right balance of care by acknowledging the demands of patienthood, the complexity of the biopsychosocial multiple health system context, and by facilitating patient partnerships that "fit health care into the larger purpose of their lives" (Leppin et al., 2015, p. 53).

Survivorship is not a smooth trip. In a study carried out in the USA at the beginning of the millennium with 4,496 patients, the incidence of psychological distress was estimated to be 35% on average across various types of cancer, across different levels of burden of care associated with different types of cancer, and across different stages of cancer progression (Zabora, BrintzenhofeSzoc,

Curbow, Hooker, & Piantadosi, 2001). A particularly noteworthy finding was the comparable levels of distress between a diagnosis with a poor prognosis and greater patient burden. While differences amongst diverse cancer sites were identified, many of the clinical issues remained similar across the sites. The lowest level of distress identified pertained to the married category confirming the power of family support during such an illness. Concluding, Zabora et al. argued that cancer patients cannot be conceptualised as a homogeneous group, even when diagnosis and prognosis are similar. This approach challenges services to accommodate to each patient's narrative. Psychosocial screening is therefore an essential component of cancer treatment to detect and address patients' anxiety and distress, not only to improve treatment outcomes and patient's quality of life but also to decrease treatment costs (Zabora et al.).

The focus on patients' total pain experienced as they go through cancer treatment led Aldaz, Treharne, Knight, Conner, and Perez (2018) to identify six pertinent psychosocial states: "diminished well-being", "perceived role changes in intimate relationships", "heightened awareness of limited time", "a new order of priorities", "taking things as they come" and "development of trust in health professionals". Multidisciplinary support services aimed at supporting patients through these states improve their ability to move from 'patient' to 'survivor' (Aldaz et al.; Applebaum et al., 2017). Notwithstanding the limitations of a study based on a small purposive sample, the psychosocial states identified in Aldaz et al.'s study provide a strong conceptual framework for investigating the experience of living with cancer:

- Diminished well-being – patients' well-being is seriously hampered by the uncontrolled treatment-associated symptoms, such as fatigue, changes

in taste and slower cognitive function, making it impossible to plan in advance or to continue moving on with life;

- Perceived role change in intimate relationships – patients and their partners transition to a patient-carer role relationship, with significant changes in intimacy, both negative and positive;
- Heightened awareness of limited time and future uncertainty – patients experience the need to live the 'now' with increased awareness of the 'present time';
- New orders of priorities – in addition to worrying about their symptoms and prognosis, patients worry about their possible shortened lives, and are driven to assess where priorities stood;
- Taking things as they come – patients developed their particular hopeful attitude and fighting spirit to deal with the uncertainty of the illness, balancing their readiness to accept support with a need to maintain privacy;
- Development of trust in health professionals – Patients develop a strong trust in the health professionals, without which they would not manage to deal with the realities of the treatment regime.

The aspect of patient psychosocial distress, namely the importance of patient care and support needs during different stages of treatment and post treatment, was also evident in several other studies (Duncan et al., 2017; Halpern, Fiero, & Bell, 2017; Johansen, Cvancarova, & Ruland, 2018; Muliira, Natarajan, & Vergara, 2016; Patterson, McDonald, Zebrack, & Medlow, 2015; Piazza et al., 2017; Singer et al., 2014). In Singer et al.'s (2013) study, only nine percent of cancer patients with a comorbid mental health condition received mental health

specialist services following diagnosis. Such low percentage is concerning considering the emotional suffering and the direct and indirect costs of mental illness. Cognitive reasoning, including reflections on previous experiences and personal beliefs, were seen by patients as increasing awareness of skills to face their new cancer challenges. Internal resilience, as well as the experiences of previous emotional adversity added flexibility and capacity to grow via the cancer path (Baker et al., 2016; Duncan et al., 2017; Halpern et al., 2017; Johansen et al., 2018; Muliira et al., 2016; Patterson et al., 2015; Piazza et al., 2017).

Ongoing supportive care-needs of patients persist well beyond the active treatment phase of cancer management (Foster & Fenlon, 2011). Unmet needs, which can increase the level of anxiety and reduce the quality of life of cancer patients, shape the cancer treatment experience. Swash et al (2017) argue for theoretically informed interventions facilitating acceptance in survivors to counteract distress in cancer care. They introduce the notion of 'psychological flexibility', which can play a moderating role between need and psychological distress (Swash et al.).

2.5 'Full-time' Patients

Studies on the impact of cancer has led researcher to ask the question: Do cancer patients need to take up a new occupation of being full-time patients? Wagstaff and McIntyre (2017) dwell on the impact of health services on a cancer patient's life. The authors query whether it is possible for someone diagnosed with cancer to remain oneself without having to become a full-time patient, and a full-time patient for the rest of one's life. Wagstaff and McIntyre quantify the liaising, setting and keeping appointments, and other treatment related tasks as involving

a minimum of 900 hours a year, a significant impact on patients' and their significant others beyond the effect of the illness and the treatment itself. These 900 hours were estimated by a wife and carer to a person diagnosed with cancer, arguing that "if you want some normality, like non-patients have, then you have to be extremely organised and knowledgeable … Patients invest everything in their treatment and survival, much of which is unrecorded and unevaluated" (Wagstaff & McIntyre, p. 59).

The concept of 'burden of treatment', initially advanced in the field of chronic conditions, was defined by Tran et al. (2012) as "the impact of health care on patients' functioning and well-being, apart from specific treatment side effects" (p. 69). Tran, Barnes, Montori, Falissard and Ravaud (2015) developed a tool to assess such burden (see Appendix G, p. 156, for diagram representing a categorisation of the burden of treatment). A survey completed by over 1,000 patients with a variety of chronic diseases from 34 countries identified numerous issues gathered under three principal areas: factors that exacerbate the burden of treatment; healthcare tasks; and consequences of healthcare tasks that imposed on patients in their daily lives. Situational, personal, structural factors, as well as characteristics of the treatment, with aspects like "my physician does not take into account my context", "I have to regularly explain my conditions to others", "all my money goes on my health aside from basic bills" to "learn to navigate the healthcare system" were examples of issues raised (Tran et al., 2015). More than a simple classification, for patient advocates like Gilly Spurrier, the burden of treatment taxonomy Tran et al. (2015) developed, is the first step in bringing together "the many different ways that 'the work of being a patient' can impact on their lives" (in Wagstaff & McIntyre, 2017, p. 59). The critical issue to

ask in this context is whether such a burden is unavoidable or whether it is possible to plan, organise and deliver cancer treatment and support services in a way that the burden of treatment is reduced. This issue is explored further with the participants in this study.

The relationship between disruption caused by health services and effectiveness of same services was studied by May et al. 2009 who proposed the concept of 'minimally disruptive treatment' described by Abu et al. (2015) as "a patient-centred approach that asks the question: what is the situation that demands medicine, and what is the medicine that the situation demands?" (p. 45). May et al. argued that the care provided in chronic illness must be less disruptive in order to be effective. The ensuing load of work of a long-term illness, described as a 'chronic workload', included factors that intensify treatment burden, such as uncoordinated appointments within clinics dealing with different conditions and complex treatment systems to which patients, or their carers, are expected to adjust their daily lives. May et al. described the work of being a patient as including:

> … much more than drug management and self monitoring. It also includes organising doctors' visits and laboratory tests. Patients may also need to take on the organisational work of passing basic information about their care between different healthcare providers and professionals. (p. 486)

Focusing on developing solutions, May et al. (2009) propose four principles to guide health services design: establishing the weight of burden; encouraging coordination in clinical practice; acknowledging comorbidity in clinical evidence; and prioritising from the patient perspective. Such standards have significant implications for health policy and practice formulation as they imply that health

services planning, design and delivery understand the patient's situation, challenging the doctor-patient relationship to share treatment goals and decision making. Only by understanding a patient's situation can disruptions for patients be minimised. It also mitigates against the one-size-fits-all approach often resulting from harmonised clinical paths, treatment protocols and standard operating procedures. May et al.'s study converges with Wagstaff and McIntyre's (2017) argument that Parson's (1951) 'sick-role model' does not provide the answers to address complex comorbidities in medicine.

Notably, the prevalent situation is rather contrary, with the expectation that a cooperative patient does all that the health treatment services expect from the patient. Such an experience is eloquently articulated by patient advocate Gilly Spurrier as follows: "There is an almost unspoken rule that a patient 'becomes their disease', and that patients should not be surprised that life is so heavily impacted. The assumption is that 'Well, you are alive, be grateful for that'" (in Wagstaff & McIntyre, 2017, p. 63). This unwritten health protocol disregards its possible negative consequences on health services outcomes and contrasts with the practice of 'minimum disruptive medicine'.

2.6 'Full-time' Impact of Treatment

The gradual recognition of patient's illness experience has led to the development of tools to measure the full-time impact of treatment. There is emerging literature on patient's feedback in the shape of Patient Reported Outcome Measures (PROMS) (Crompton, 2018). PROMS can enable improvement by obtaining information that fill the gap between the clinical reality and the patient's world. These questionnaires measure patients' perceptions of

their experience while receiving treatment and care. Patient Reported Experience Measures (PREMs) are questionnaires measuring the patients' views of their health status. PREMs and PROMs thus capture patients' subjective experience. Such methods have been used for quite some time in clinical treatment trials to measure corresponding physical symptoms and psychological problems. PROMs are seen by some researchers as the solution to putting the patient's experience at the centre of research, clinical decision making and treatment availability if the data gathering on patients' quality of life is carried out systematically (Haywood, Wilson, Staniszewska, & Salek, 2016; Wilson, 2018). The argument for standardisation of patients' subjective experience, though seemingly contradictory, has found itself in mainstream healthcare literature and goes as follows: "Patient quality of life data ... must be standardised and gathered on a massive scale, so that whole pathways of care in every disease can be guided by what has actually helped patients live fulfilled lives" (Crompton, p. 54).

PROMs and PREMs can lead to the patient perspective becoming the pumping heart of health research. However, advocates for PROMs are driving the concept more for patients' informed choices than for monitoring (Crompton, 2018). It is necessary to critically assess the value of a few weeks' added life in contrast to the impact on patients of 'exciting new therapies'. Research has shown that patient involvement in PROM development is a must for valid patient-centred PROMs; however, it is not always the case (Wiering, de Boer & Delnoij, 2016; Wilson, 2018).

The PREMs and PROMs' notion is a theme overarching into survivorship as it delves into the provision of information on patients' quality of life over long time

periods. The challenge, particularly in the survivorship aspect, is to make the capturing of such data as uncumbersome as possible, harmonised and standardised, in order to influence future clinical decisions. As previously argued, the notion of standardising a patient's subjective experience sounds contradictory as how can a personal experience be standardised? Such an approach has significant limitations as the patient's subjective experience has to fit into standardised categories, which may limit the understanding of the uniqueness of a patient's experience with cancer. Research approaches such as IPA may be used to bridge the two concepts.

2.7 Reprioritising What is of Value in Living

With challenges that cancer and its treatment present on one's life, cancer patients conceivably develop a new order of priorities, heightened by an increased awareness of limited time. Baker et al. (2016) presented the original thinking that existential issues are core to the cancer experience, including facing one's morality, finding meaning in the illness, and questioning one's sense of identity. Normality was described as meaning different to different patients, varying from "getting back to routine" and "as if nothing has happened" to "adjusting to a new self, shaped by cancer" (Sandsund et al., as cited in Baker et al.). Participants fought to maintain normality although some admitted that it was "a new type of normality", with the cancer becoming a "defining component of identity", even post treatment. In fact, out of the 28 patients studied 17 described living the two realities of living as if cancer did not exist for them, "a blip" in their life, at the same time reasoning within a context of vulnerability, and a life shortened with cancer. The majority held different, often contradictory, views

about their identity, irrespective of where they were at in the cancer treatment trajectory (Baker et al.). This duality of experience in no way implies that patients interviewed were in denial; rather, the researchers argued for a patient's normality to include parallel realities coexisting (Baker et al.).

Salander (2012) developed Winnicott's (1977) notion of an 'intermediate area to cancer' between the external and internal patient realities, to describe patients' coping with the trauma of the illness. Salander believed that this 'intermediate area' provided patients with a sheltered space when facing the distress of cancer. Baker et al. (2012) comment that their findings show similarities with the above concepts; however, their results go beyond the initial arguments, showing that the conflicting responses to cancer can coexist. Findings also brought out the importance of maintaining continuity with the pre-cancer reality and identity of self. The use of the 'intermediate area' can serve as an important state of adjustment helping patients maintain a hopeful perspective in the face of the sternness of their condition (Baker et al.).

The above findings highlight the need for professionals working with cancer patients at any stage of their treatment to be sensitive and open to the patients' new reality and normality, possibly living with seemingly contradictory perspectives. Such themes, though inward looking, are essential reflections for understanding what health and support systems and services are best indicated to meet patients' and caregivers' needs throughout the cancer trajectory (Aldaz, et al., 2018; Applebaum et al., 2017; Duncan et al., 2017; Halpern et al., 2017; Johansen et al., 2018; Muliira et al., 2016; Patterson et al., 2015; Swash et al., 2017).

2.8 Cancer Patients' Experiences on Significant Others

This review so far has primarily centred on how cancer patients' illness and treatment experience shape their quality of life. Such aspects also leave a weighty effect on the caregiver. As already cited above, Aldaz et al. (2018) identified the changes in roles in a cancer patient's intimate relationships as central to the cancer treatment experience. For family members, taking care of a patient with cancer throughout the treatment trajectory has its challenges, having to face both the burden of disease and the burden of treatment. A partner's role changes significantly, particularly in cancer relapses or in palliative care, with a higher possibility of emotional distress that can easily go unnoticed, overshadowed by patient's continuum of needs, leading to the significant other/carer to experience a poorer quality of life (Mazanec, Flocke, & Daly, 2015).

The ability of caregivers to provide practical and emotional support to cancer patients is affected by their stress levels (Northouse, Williams, Given, & McCorkle, 2012). Research has shown that caregivers can be positively supported to fulfil their role; conversely, when a caregiver's mental and physical health is at risk there is a negative impact on the patient's optimal care (Northouse et al., 2012). Different research studies converge on the importance of caregivers' involvement in cancer programmes, an involvement that makes the service provision more wholistic (Heckel et al, 2018; Johansen et al., 2018; Lee, Yiin, & Chao, 2016; Northouse et al, 2012; Piazza et al., 2017).

In chronic illnesses family caregivers are the backbone of the social care delivery system. A USA study with 111 caregivers of cancer patients highlighted the reality that with the advancements in cancer research much of the cancer care is offered on an outpatient basis, with an additional load on caregivers (National

Alliance for Caregiving, 2016). Research indicated that caregiving is demanding on the physical, emotional and also the financial aspect, referred to under the notion of 'caregiver burden' (Kim & Schulz, 2008; Northouse, Katapodi, Song, Zhang & Mood, 2010). Cancer caregivers are generally caregivers for approximately two years, considered a relatively short duration of caregiving, when compared to chronic illnesses such as Alzheimer's; however, the burden is high with 62% being classified as living in a high burden situation. Forty three percent perform complex medical or nursing tasks without any training or preparation for it (National Alliance for Caregiving). Significant others often experience a psychological burden that goes beyond the trauma of the critically ill patient, particularly when topics related to end of life are evaded (Siegel, Hayes, Vanderwerker, Loseth, & Prigerson, 2008; Williams & McCorkle, 2011).

More of these studies on the impact of illness on caregivers underline the significant contributions made by family caregivers and accentuate the importance for healthcare professionals to be sensitive to such caregivers' needs; based on studies carried out in many different countries, it can be concluded that cancer patients primarily rely for their day to day, hospital and emotional support from their families, irrespective of the culture and country (Halpern et al., 2017; Nissen, Trevino, Lange, & Prigerson, 2016; Rha, Park, Song, Lee & Lee, 2015).

2.9 Patient-Centred Care

The substantial research underlining the reality of patients and their families struggling with illnesses such as cancer and their treatment regimes inevitably refocus the centre of health services. The most notable shift in patient care in the past two decades was the patient-centred care concept with patients seen as

equal partners in medical decision making (Hodgkin & Taylor, 2013). This refocus is the value of patient centred care, where patients are informed participants in treatment care, a stark contrast to the traditional medical paternalism or sick-role model. For most patients, patient centred care is about seeing the person holistically rather than simply focusing on the illness, emphasising "… joined up care and the importance of compassion, respect, and dignity" (Hodgkin & Taylor, p. 7). The 2010 UK White Paper entitled 'Equity and Excellence: Liberating the NHS' was heralded as the best official document to date in the UK to place the patient as the primary focus (Hodgkin & Taylor). This White Paper followed a National Cancer Alliance project on gathering the views of UK cancer patients with various recommendations emphasising patients' relationships with the health professionals. In their feedback, patients emphasised their doctors' humanity, sensitivity and approachability as the critical qualities "to form a working relationship where information and views could be easily exchanged" (National Cancer Alliance, 1996, p. 97).

Nevertheless, so many years on, the medical model still dominates the UK National Health Services, similar to the prevalent situation in other countries. Various reasons have been given for this reality, notably the reality that illness is in itself such a disempowering situation that renders the challenge for patient centred care tough to take up. Hodgkin and Taylor (2013) argue that the empowering of patients will likely happen once the population of individuals with chronic and disabling conditions start demanding a social model of care. In such an approach, patients' own resources and those of their significant ones, as well as community resources, will be sought to assist the individual to stay well and functioning. What may also drive this major shift is the increase in transparency

in medical performance as well as digital technology (Hodgkin & Taylor). The WHO promotes patient centred care on the basis of evidence showing that it improves the quality of care (Richards, Coulter & Wicks, 2015). The WHO claims that the challenge to have patient centredness on board is “one of overcoming system inertia and paternalism” (Richards, Coulter & Wicks, p. 1). Patient centredness can only happen if health systems identify better ways to tailor support that reduces dependency. Further, patient-centred care requires health systems to listen to patients and guarantee that patients’ voices are listened to in medical fora, with services keeping the burden of treatment on patients as ’minimally disruptive’ as possible.

2.10 Person-Centred Care

The notion of ‘patient-centred care’ has further developed into a ‘person-centred care’ approach. Advancements in care and cultural changes have contributed to a shift in the personal, social and economic responsibilities people with long term illnesses handle alone, or with their family and the wider community. This shift on to the patient is referred to as patient-led care; patients who are ’activated’ to obtain knowledge, obtain skills and gain confidence to manage their health effectively. Such ’activated’ persons stand a higher chance of adopting healthy behaviours, with better health outcomes and care experiences, with possible even better use of resources (Eaton, Roberts, & Turner, 2015).

Person-centred care requires coordination. Public health services are being challenged with this concept to provide comprehensive and coordinated interventions for different persons that come in contact with the medical setting, a varied range of interventions that are organised to provide a tailored response

for each person. Comprehensive programmes that have been developed internationally on these lines include the TEAMcare in the USA and the Flinders programme in Australia. Such ways of operating in health care requires new thinking with an acknowledgment that whole systems approaches are imperative.

This challenges of person-centred care was argued by Eaton, Roberts and Turner (2015) as follows:

> Many clinicians believe they already practice in a patient centred way, though patient surveys tell otherwise ... At the other end of the spectrum, around 40% of people report a poor understanding of their conditions or treatments, are lacking in confidence, or feel overwhelmed … Nevertheless, these individuals are still managing their health day to day and have the most to gain from additional support. (p. 2).

A qualitative study carried out with patients and professionals in hospital wards and primary care centres delivering person centred care in Sweden showed that patients value human relationships over formal aspects of agreed goals and care planning, with person centred care increasing a person's confidence in professionals. Person centred care also showed good elements of communication and cooperation (Wolf et al., 2017).

2.11 Health Literacy

Person centred care presumes health literacy, the capacity to self-manage effectively. A patient's engagement level with health care services is a determining element as it affects health outcomes and improves health care experiences, with less usage of valuable resources (Wassong & Coleman, 2014). Health literacy describes a service user's ability to grasp the demands health mandates from its users (Peerson & Saunders, 2009). This concept was first

coined in 1974 within the context of health education in relation to the health system (Ratzan, 2001). The WHO defines health literacy as “the cognitive and social skills which determine the motivation and ability of individuals to gain access to understand and use information in ways which promote and maintain good health” (WHO, 1998, as cited in Peerson & Saunders, 2009, p. 286). The essence of this definition and other definitions of health literacy is the notion of access to information and the ability to master it. The level of education, access to correct information and problem-solving skills have been found to promote patient participation in health decision making, with patients of a higher education level taking a more active role (Sainio, Lauri & Eriksson, 2001). Health literacy is a critical skill that assists individuals to become active participants in their health care (Jacobs, Ownby, Acevedo & Waldrop-Valverde, 2017) This concept has been closely connected to the social determinants of health, health behaviour and health outcomes, as well as health service use (Sorensen et al., 2013).

Health Literacy is at times termed ’health confidence’, ’patient activation’, ’patient self-efficacy’, ’self-care’ and ’self-management’, besides ’patient engagement’ (Wassong & Coleman, 2014). In the field of oncology, poor health literacy has been linked to ineffective communication with consultants with a potential for greater anxiety (Koay, Schofield & Jefford, 2012). Given that low levels of health literacy in relation to chronic illness affect both health processes and outcomes, due attention to health literacy is necessary in cancer treatment, particularly considering its complexities.

2.12 Co-production and Cancer Treatment

The various developments that have taken place in healthcare in general, and also reflected in cancer treatment, point towards an increased recognition that some level of patient partnership is necessary (Batalden et al., 2016). Concepts already discussed above such as patient-centred and person-centred care represent different attempts to promote patient participation. Donabedian's focus on health services as processes push the role of patients further into the core of health services production. Back in 1992 he had argued foreseeably that "we should conceive of practitioners and patients as jointly engaged in the production of care" (Donabedian, 1992, p. 250). A process that involves the patient necessarily implies that the patient is a co-producer in the process and therefore a co-producer in the outcome resulting from that process (Turakhia & Combs, 2017). Co-production in health care services, also referred to as co-creation, is a model of service delivery constructed around "the sharing of information and on shared decision making between the service users and providers … on the assumption that both parties have a central role to play in the process as they each contribute different and essential knowledge" (Realpe & Wallace, 2010, p. 5). Co-production assumes a focus on individual needs, depends on continuing relationships between professionals and patients, recognises the important contribution of patients in health processes for successful outcomes, and empowers professionals and users alike to work collaboratively with each other (Realpe & Wallace).

In a study involving five Dutch hospitals, co-production was considered as contributing to quality improvement through various processes (Vennik, van de Bovenkamp, Putters & Grit, 2016). Similarly, Turakhia and Combs (2017)

consider co-production as having the potential to add value to health services not only at the patient-clinician level but also in developing health systems that deliver better outcomes in general. The argument here is that by recognising patients as contributing partners in their care and not just consumers of services, better outcomes can be achieved not only for the patients concerned but correspondingly systemwide.

Co-production as a concept does not come without its challenges or limitations. Batalden et al. (2016) identify five such issues, namely; diversity in patient desire and capacity to engage in co-production; reconciling co-production with responsibility and accountability for outcomes; shifting care responsibilities on patients and families; co-production increases variation and challenges the benefits of standardisation; day to day challenges in healthcare delivery yield a healthcare culture resistant to power sharing. These challenges were also recognised by Palumbo (2016) in a systematic literature review on co-production in health care. Notwithstanding the practical difficulties identified to implement co-production, Palumbo concluded that the "scientific literature is consistent in claiming that co-production of care paves the way for increased health outcomes, enhanced patient satisfaction, better service innovation, and cost savings" (p. 72).

2.13 Managerial Concepts of Health Care

With patient and person-centred care, and more so with co-production, the shift is on the patient's voice and patients' advocacy groups and user groups. Being person-centred is more than simply a correctly worded statement. The concept needs to be spelt out into processes and practices where the needs of the

patients are met most effectively. In June 2018 the first Haematology Community Advisory Board (Hem-CAB) took place in Stockholm where senior representatives from nine pharmaceutical companies active in haematology and eleven advocacy networks representatives convened to discuss topics of significant concerns to patient advocates (Wagstaff, 2019). The Workgroup of European Cancer patient Advocacy Networks (WECAN) is another similar network made up of 21 European/International cancer patients advocacy organisations (Wagstaff).

Patient community boards are increasingly being seen as the way forward to better address the needs and wants of patients. However, patient involvement is complex as long-standing patient representatives can lose their independent perspective. Patient representatives also need to produce more evidence-based advocacy (Crompton, 2016).

A health organisational management set up can bridge the gap between the organisational goals and the patients' reality by analysing how much its health service set up is aligned towards patient and family focused care and to the medical research world (Ginter, Duncan & Swayne, 2018). In management there are frameworks that shape the strategic planning of an organisation. People make policy, which is influenced by context and actors. Health policy converges with environmental and economic market structures. There could be value added service delivery strategies for patients through clinical operations and marketing. One such strategy within clinical operations is the understanding of the processes and choosing the one most suited for patients' care, known as 'clinical pathways' (Yamazaki, Ikeda & Umemeto, 2011). Such clinical pathways involve all health care professionals in the visualisation of the patient's health-care process, aiming

for an increase in communication as professionals share information on the patient's process. Clinical pathway analysis applies "critical-path methods used in industrial process control to clinical processes" (Ginter et al., p. 332). There is, however, the risk that these clinical pathways focus more on standardisation of quality measures than on the adaptation of care to meet a patient's individual needs.

Another management approach to improving health services outcomes is the 'Continuous Improvement Strategy' that refers to a process whereby incremental changes targeting efficiency and quality are adopted (Ginter et al., 2018). Similar to the challenge described for clinical pathways, this management approach risks being more operationally driven than centred on the patient's idiosyncratic reality.

Patient satisfaction studies are widely used in health management as part of 'After-Service Strategies' designed to facilitate patients' feedback to health authorities. One comprehensive patient satisfaction framework is the 'Patient Satisfaction Strategy Map' (PSSM) that ties patient satisfaction to the before and after actions (Ginter et al., 2018). Patient storytelling can be another source of direct feedback from patients recounting their experience of contact with health services.

Patient portals allow patient participation in their health management. Their aim, when originally introduced, were to improve patient outcomes through patient satisfaction. Portals can also be educational instruments sending information to patients, serving as a reminder for appointments and function as modules of the provider's electronic medical record. Research on portals has linked their effectiveness in medical adherence, self-management of disease and

improvement in preventative medicine with some evidence of improved health outcomes (Ginter et al., 2018).

2.14 Humanity and Cancer Care

There is a link between people's lifestyles, their familial and social context and their illness. However, this link is often missed with medicine often focusing on the person's pathology and not the illness, diagnosis and health issue in the socioenvironmental context of the individual (Nolan, 2003).

Sacks (1991) states that:

> In present-day medicine, by contrast, there is an almost exclusively technical or mechanical emphasis, which has led to immense advances, but also to intellectual regression, and a lack of proper attention to the full needs and feelings of patients. (from the Preface to the Original Edition).

Asking for information allows better identification of the illness, how that illness is affecting the patient's daily life and even to understand the person's understanding and beliefs about the problem or illness (Sacks, 1991). The patient is searching for information; however, the information being sought for is generally more related to diagnosis, prognosis and the impact on their lifestyle rather than what doctors believe patients are searching for, namely treatment information and drug therapy (Nolan, 2003).

Health and care services face the challenge of having to adapt to complexity, uncertainty and nonlinearity. To achieve such adaptation, two seemingly incompatible features counter each other, namely the standardisation of systems and the flexibility of creativity. Decades of focus on technological development, cost containment, and assessment and accountability, have not been sufficient

to address key issues in public health services delivery. Black (2018) argues for the importance of recognising that health care services are systems comprising of human beings and that human creativity has the potential to solve problems much better than top down approaches.

The implications of this perspective are significant in that it recognises the limitations of systems and emphasises the importance of the human relations that mould the systems. Such a notion resonates with Donabedian's (2003) argument that mechanisation and specialisation cannot replace the human will to the pursuit of quality.

2.15 Conclusion

In his inspirational work "Being Mortal: Medicine and What Matters in the End", Gawande (2015) stresses the centrality of the patient's experience in all matters pertaining to health and wellbeing:

> Our most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one's story is essential to sustaining meaning in life; that we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters of everyone's lives. (p. 242)

The literature reviewed suggests a number of important considerations pertaining to the experiences of cancer patients and their families. All studies reviewed corroborate the mammoth bearing that cancer has on persons living with the illness and their families. Being a cancer patient was described as a 'full-time' endeavour with the burden of the treatment adding to the burden of the illness itself. The move towards health services systems that are more cognisant of the

service user's reality involves transformations in health management practices but also depend on increased patient health literacy. Both these changes face a number of challenges.

On the one hand, health management systems operating within a positivist scientific paradigm are more likely to favour standardisation of quality systems that are capable of integrating patient outcomes and experiences in a format that allows for clear measurement and analysis. The person-centred idiographic approach, on the other hand, depends on an active and health literate patient that takes full ownership and control of the treatment journey, an undertaking rendered extremely arduous by the reality of the illness and the corresponding treatment. When health services create supportive partnerships with patients, not only do patients experience better outcomes but "can make their greatest contribution to enhancing the quality of care, even as we make ours" (Donabedian, 1992, p. 251).

While the research literature has developed a significant understanding of what it means to live with cancer both during and after treatment, it is rather sparse on describing and understanding the way cancer patients experience the health services that treat them and the way the interaction between the patient, the patient's support structure, and the health services system condition the treatment experience. Understanding this experience from an idiographic perspective can provide health management with a unique insight to inform the planning, design and delivery of oncology services.

In the following chapter, the research strategy, design and methods of data collection developed to answer the research question of this study, are described and discussed.

Chapter Three: Methodology

This chapter describes the methodology used in this study to explore the lived experiences of cancer patients, their families and their significant others through their treatment journey. The rationale for choosing interpretative phenomenological analysis to engage with the reflections and interpretations of cancer patients' experiences is explained. The overall research strategy, design, methods of data collection and analysis, and the complete research process are described in detail.

3.1 Research Strategy

The research question guiding this study shaped the qualitative research strategy adopted. Understanding the health care services experiences of a cancer patient necessitates a thorough idiographic approach that is capable of capturing the unique construction through which each participant interprets one's reality. Any significant life experience can be studied at different levels or hierarchies. At a first level, one may give a detailed account of the experience. Alternatively, the research may try to capture the storyline or narrative of the experience. Major life experiences also drive people to reflect on the significance of what they would be experiencing and living through. This study is interested in engaging with the reflections and interpretations of cancer patients, their families and their significant others as they try to make sense of their health service users' experience and the biopsychosocial impact of the experience (Grassi, Spiegel & Riba, 2017).

Conducting such research in a qualitative framework is key to enable the researcher to grasp a thorough, in depth comprehension of intricate issues. Such a strategy focuses on the rich accounts of the phenomenon under investigation in contrast to quantitative research strategies that use data quantification to describe generalisations and associations between variables that can be quantified, transforming the phenomena to numerical values for statistical purposes (Barnett-Page & Thomas, 2009). The data in qualitative research is generally collected in a natural environment, giving importance to both the subjects and researcher's interpretation of the phenomenon in the analysis process (Smith, Flowers & Larkin, 2009).

3.1.1 Phenomenology, hermeneutics and idiography

Gaining an in-depth understanding of the experience of cancer patients and their support structure as they interact with the health care delivery system implies the interpretation of an individualised phenomenon. In this respect, the research question dictates an epistemology and ontological approach grounded in phenomenology, hermeneutics and idiography (Smith et al., 2009).

3.1.1.1 Phenomenology

The phenomenological approach allows the researcher to examine how cancer patients, their families and significant others make sense of a life-threatening illness experience that engages them with the health services for a substantial part of their life. Phenomenology is a philosophical approach to studying people's experiences. The particular interest is in understanding what the experience of being human is like, in all its varied aspects, but in particular in what matters to human beings and in what shapes their world. Four major phenomenological

philosophers, Husserl, Heidegger, Merleau-Ponty and Sartre, each developed different aspects of this philosophical reasoning (Tuffour, 2017).

Husserl, with his phenomenological inquiry, focuses on that which is experienced in the consciousness of the individual, arguing that reflective inquiry enables the researcher to go beyond the values, goals and instrumentalities evident in matter under investigation, and enables one to "grasp the corresponding subjective experiences in which we become 'conscious' of them ... For this reason they are called 'phenomena'" (Husserl, 1927 para. 2., as cited in Smith et al., 2009, p. 13).

Heidegger, a student of Husserl, focused on the concept of 'wordliness', the physically-grounded (what is possible) and the intersubjectively-grounded (what is meaningful) options (Smith et al., 2009). For Merleau-Ponty the practical activities and relationships "the physical and perceptual affordances of the body-in-the-world" (Smith et al., 2009, p. 19) are the most significant. Because for Sartre human nature is more about becoming than being, the human nature has a choice, in that the individuals are responsible for creating their own reality. It is a reality lived in the complexity of the context of the individual life, giving importance to the biographical history and the social climate in which the individual acts (Smith et al., 2009).

The asset of phenomenological research is its ability to capture "the ambiguity, poignancy, complexity and richness of lived experience" (Finlay, 2009a, p. 480), with the potential of transforming both the researcher and the participants (Finlay, 2009b).

3.1.1.2 Hermeneutics, interpretative phenomenology, and double hermeneutics

Phenomenological research implies an interpretivist epistemology and constructivist ontology. Knowledge about the human experience is gained through an understanding of how that human experience is interpreted. Such an understanding can go beyond the mere description of the phenomenon being studied. Smith et al. (2009) demonstrate how the phenomenologist can interpret the appearing phenomenon, another central principle in hermeneutic phenomenology (Finlay, 2009a).

The term interpretative phenomenological analysis implies the dual facets of the approach (Smith, Jarman, & Osborn, 1999) with the joint reflections of both participant and researcher forming the analytic narrative (Smith, Flowers, & Osborn, 1997). In this respect, the notion of a double hermeneutic explains the process through which the researcher interprets the subjective interpretation being studied. The reality being examined is therefore constructed through different levels of interpretation, implying a constructivist ontology.

3.1.1.3 Idiography

The phenomenological approach also implies an emphasis on the distinctiveness of the individual experience; for instance, the way different people experience a phenomenon like pain is subjective. The level of subjectivity and individuality increase with the complexity of the phenomenon being studied. This idiographic approach emphasises the actual experience an individual is going through and the personal account of same (Smith, Harré' & Van Langenhove, 1995). Harre' (2016) describes idiography as "studies of individuals one at a time, without reducing any of them to an instance of a common type" (Harre', 2016 p. 164).

3.2 Research Design

Several approaches within a qualitative research strategy can be explored in choosing a research design, including case studies, cross-sectional, longitudinal, comparative and quasi-experimental approaches (Bryman, 2016). Considering the philosophical underpinnings explained above, this study adopted an interpretative phenomenological analysis design (IPA). IPA is an idiographic approach, focusing on the depth and distinctiveness of each participant's experience rather than being concerned with representation, generalisation and replicability. IPA studies in detail what the experience of a person is like and the sense that any particular person makes of what is being experienced. IPA is interested in understanding experience in its own right; the individual's experience. Researchers in IPA try to understand what happens when the everyday experience takes on a particular significance for different individuals. There is an understanding of a hierarchy of experience in IPA, with an interpretative undertaking.

In IPA, the assumption is that everyone is unique and therefore everyone should be studied in an individual way, lending itself for a more complete understanding of the particular individuals being studied; thus, this method enables the researcher to hear the individual's experience of the health services (Smith et al., 2009). The IPA research design provides the researcher with an approach focused on interpreting the participant's interpretation of their experience in the context of the research question being asked. Cancer patients and their support network experience the cancer in the context of the health services they engage with in the treatment of their cancer. They try to make sense of their illness and the treatment experience that, in a rather short time, takes over their life.

Understanding and interpreting the cancer patients' understanding of their treatment experience can provide a unique perspective on the health delivery system.

IPA is increasingly being used in areas of study concerning cancer related themes (Pringle, Drummond, McLafferty & Hendry, 2011). Numerous studies are showing how IPA is well suited to understanding patients' experiences of their treatment journeys. Comprehending the lived experiences of patients is increasingly being recognised as fundamental to enhance patient-reported outcomes and service-level performance indicators (Assing Hvidt, Raun Iversen & Ploug Hansen, 2013; Halverson et al., 2015; Levy & Cartwright, 2015; Maguire, Stoddart, Flowers, McPhelim & Kearney, 2014; Pearce, Thøgersen-Ntoumani, Duda & McKenna, 2014).

3.3 Research Methods and Process

For IPA, the most suitable method for data collection is qualitative interviewing, described as a flexible and powerful tool that allows for new areas of research (Pope & Mays, 2006). IPA studies are typically conducted with a small number of participants given the focus on gaining in-depth understandings that may contribute to theoretical generalisations, but not for statistical generalisations. Smith et al. (2009) consider the sensible number of participants for an IPA research project to range from three to six. They argue that the small number is necessary to allow for the level of analysis typical of an IPA study. Such an approach is equated to having three case studies in which the three cases are analysed as individual cases, and also comparatively, to highlight convergences and divergences.

3.3.1 Research participants

Research was carried out with six cancer patients, equally divided between men and women. Given the focus of this study as also including families and significant others, the choice of whom to involve in the study was left to the primary participants. Participants chose to be part of the study either alone or with any other significant others they opted to include.

The choice of number of participants requires a brief explanation. IPA's strength is in its idiographic emphasis and IPA studies focus on the depth and richness of the particularities of individual lives rather than aiming for generalisability. In this respect, interviewing a small number of participants is preferred to a larger number of participants (Eatough & Smith, 2017). Although the possibility of selecting a larger number of participants was considered, the choice to work with a small group of cancer patients was taken to facilitate a truly IPA approach.

Potential participants had to meet the following inclusion and exclusion criteria:

1. Cancer patients who fell in the 35-65 age bracket, and who were users of the Malta National Health Services. The choice of the age group was intended to exclude concomitant issues related to young adults, and comorbidity issues more common with elderly persons;
2. Cancer patients who were diagnosed with cancer during the previous 4 years, had finished their main treatment to avoid risk of secondary trauma, and were still in contact with the OC services during the study period. This time period ensured that participants would have had a fairly lengthy exposure to the different health services without the experience being too

far removed to allow for a good memory of their involvement with the sector;

3. Cancer patients who had the cognitive ability to reflect on their experience given the IPA nature of this study;
4. Cancer patients who were ready to consent to the research process and to having their interviews audio recorded.

3.3.2 Participants' involvement

Initial contact with potential participants was carried out by the oncology medical consultants, namely the consultant who already knew the patient as part of the health service. Given the researcher's professional relationship with the oncology consultants, a preliminary discussion between the researcher and the consultants clarified the nature of the service users that could best contribute to the study. The choice of the patient's consultant as the gatekeeper was considered to be the right choice given the good rapport that would have already been established between the consultant oncologist and the patient. The consultant's knowledge of the patient and the relationship of trust between the consultant and the patient ensured that only patients who are capable of making an informed decision of whether or not to participate, and had the cognitive ability required, were contacted, and that potential participants contacted by their oncologists were at liberty to opt in to participate in the study. While the consultant made the initial invitation to patient to consider participation in this study, the researcher was available for any clarifications about the study. The potential participants were asked by the consultant to think about the research

participation prior to getting back to the researcher with a reply. It was made clear to all subjects that they could always withdraw from the study at any time.

Once the participants had been identified and made contact with the researcher, the interview process could commence. The nature of an IPA interview is generally semi-structured, informal, allowing participants time to develop a hierarchy of interpretations on the subject matter, their experience of the illness and the treatment journey, their reflection on the significance of this major happening in their life, and their interpretation of how they lived their engagement with the health services. Participants were also given the option of choosing whether they wanted to involve any of their family or significant others in the interview process and each participant's choice was fully respected. In this respect, participants could also request for the interviewer to have separate interviews with family members or significant others. The in-depth interviews provided a rich personal account of their engagement with the health services; participants were provided with an opportunity to speak freely and reflectively as they told their stories of the treatment journey, developing their ideas and concerns as the process proceeded. The interviewing time in total equalled 14 hours with a minimum time of 60 minutes and a maximum of 105 minutes, with a median of 95. There were seven interviews in total, with a separate additional interview having been carried out with one of the participant's wife (Thomas and Maggie).

The interviews took place where participants were most comfortable, be it home, a hospital interviewing room, or any other practical setting participants choose. Interviews were audio recorded with participants' consent as IPA requires a verbatim record of the data collected.

3.3.3 Instrumentation

An interview schedule was prepared, in both Maltese and English, to allow participants the most comfortable choice of language to converse in describing their unique experience (see Appendices C & D). Questions were open ended with suggested additional questions included. Using semi-structured interviews was imperative for such a study, allowing the maximum flexibility for participants, the 'experiential experts', to tell their story (Smith et al., 1999). The type of questions were selected after studying thoroughly the IPA proposal of question set up. IPA proposes different kinds of questions for in-depth interviews like the descriptive and narrative type of questions, and recommends using such multiple styles of questions in the interview schedule. The researcher ensured that such different types of questions were included (see Appendix E). A pilot interview with a person who has been experiencing care as a cancer patient in the Maltese health system for the past years was conducted to test the flow of the prepared interview schedule. The pilot interview also served to assess the atmosphere created by the flow of the questions and the comfortableness generated. It also had the intent to assist the researcher prepare for the actual study interviews.

3.3.4 Language used

Participants had the freedom to choose their language of choice, Maltese or English. In fact, the interview schedule was prepared in both languages (see Appendices C & D). All six participants and their significant others preferred the Maltese language and thus all transcripts were done in the Maltese language. Keeping to the language the participant chose in the interview is salient as a translation runs the risk of losing the chosen meaning the participant wanted to

specifically convey in conversation with the researcher, particularly in the context of the narration of a vulnerable health experience. In IPA hearing and reading the interview as it was conducted is expected to provide new insights. While reading the transcript the researcher focuses on the content and on the language used and the context in which the phrases were said (Pietkiewicz & Smith, 2014).

3.3.5 Data analyses

Data analyses followed the method in accordance to Smith et al.'s proposal (2009).

IPA involves both thematic development and coding (Larkin, Watts & Clifton, 2006). The analysis commenced by preparing a transcript of each interview. The transcript was divided into three columns with the recorded data on the left column, a middle column with some exploratory notes reflecting on the interview content and process, and emerging interpretative themes on the last column. The process commenced by reading the transcripts meticulously, followed by notes added as initial exploratory steps. Semantic content observed in the transcripts, such as metaphors and language used by participants, were noted down in the third column (see sample in Appendix H). Such process was repeated for each interview. At the end, when all transcripts had undergone such a detailed, meticulous process, the themes from all interviews were collated and amalgamated (Smith et al., 2009).

Writing each transcript, sequentially, allowed the researcher to engage deeper with all the interviews carried out. In IPA the researcher is meant to engage in an interpretative relationship with the transcript (Smith et al., 1997). Furthermore, such engagement occurred through repeated reading of the transcripts.

Pietkiewicz and Smith (2014) described this process as engaging the researcher in oscillating between the emic and etic perspective in that “IPA aims at giving evidence of the participants’ making sense of phenomena under investigation, and at the same time document the researcher’s sense making” (p. 366).

This process led to the second stage analysis in IPA (Smith et al., 2009) where note taking and the search for themes and questions that emerge occurs, followed by emotions that are triggered, the focus on the language use and other significant matters, that are sparked by the interview and by the relationship between the participant and the interviewee. IPA analysis moves to the third stage, which is what the researcher in this study did, where the transcripts were studied further in order to identify the patterns of meanings identified, to grasp the participant’s experience, with emergent themes grouped together according to common subject matters. The emergent themes from each individual transcript were then grouped to the other transcripts in clustered emergent themes to observe consistencies and variances brought out in such study; IPA tends to focus on the examination of divergences and convergence of small samples (Brocki & Wearden, 2006). The emergent themes were noted on the data item, with superordinate themes developing from such emergent themes.

Once the coding and theme development was completed for each data item, the researcher worked with superordinate themes across the dataset developed from all the transcripts (see quotations in both Maltese and English in Appendix F). Commitment and rigour were adhered to during the in-depth interview carried out with each participant and then during the systematic in-depth focus on each individual story (Yardley, 2000). Openness to seeing the experiences through

the participants' eyes was kept in mind at all times, with researcher being careful and sensitive to the individuality in the analysis of each participant's data.

Rather than keeping to Participant 1, 2 etc, each participant was given a fictitious name, unrelated to their real name to ensure anonymity (Smith et al., 2009). Researcher perceives calling a participant by a name facilitates a better connection to be established between the reader and each participant.

3.3.6 Limitations of the study

Having a small sample does not lend itself to generalisation and representation. The focus of this study was to zoom into lived experiences of individuals turned patients following their cancer diagnosis, with the goal of presenting possibilities of some lived realities. Duncan, Hart, Scoular and Bigrigg (2001) suggest that IPA research provides some insightful reflections while Touroni and Coyle (2002) state that such methodologies achieve a specific and deep knowledge.

The key question asked in reflecting on possible limitations of this study concerned the extent to which the experiences captured in this research can be considered as typical of cancer patients. This question is difficult to answer given the highly subjective nature of any illness and treatment journey. In all probability, the experiences of this study do not reflect those of cancer patients particularly those without the cognitive ability to reflect on their illness and treatment and of those without basic health literacy. Nor do they necessarily reflect the experiences of young people and older persons, although various outcomes of this study may still be germane to such groups.

In summary, the limitations of this study emanate from its idiographic nature, which is, at the same time, its main strength.

3.4 Ethical Considerations

This research was carried out after seeking and obtaining approval from the Faculty of Health Sciences Research Ethics Committee and from the University's Research Ethics Committee. For such approval permission had to be granted from the OC's medical consultants and management as well as MDH research committee, to be able to access subjects from within the OC (see Appendix I).

The study involved the participants in revisiting in detail experiences related to their cancer treatment journey. The experience of talking about one's treatment experience could have brought about emotional distress to participants. The researcher, being a professional in supporting cancer patients in their emotional difficulties, provided a major reassurance to participants. In addition, had further psychological support become indicative during the research process, arrangements with the Oncology Psychology Services were made to facilitate immediate access. It was also imperative for participants to feel in full control over their participation in the study with assurance of safety, privacy and confidentiality. An information letter was read to each participant (see Appendices A & B) where the description of the research, the process and the voluntary nature of the research was explained, following which, if the participant was in agreement a Consent Form (see Appendices A & B) was handed to each subject to sign. The right to stop at any point in the research was emphasised in both letters and also stated verbally. Each subject kept a copy of the Consent Form, with contact details of researcher and her supervisor included.

The research data was carefully anonymised at all levels of data management, data analysis, and report writing, to protect the subject's identity. All names, including names of consultants and other persons mentioned in the interviews

were eliminated; a highly important element considering the context of Malta and its smallness. Permission from participants for interviews to be recorded was sought; recording of the interviews permitted a natural flow of conversation in the semi-structured interviews. The interviews were not all carried out in the same time frame, following recommendation by the IPA method, and this gave the possibility of the interview experience to mature with every interview. The recordings, written observations and transcripts were kept under lock and key throughout the research, with access only to the researcher and supervisor. All records of the interview data will be destroyed upon completion of study in accordance to the time period stipulated in the consent forms.

3.5 Role of the Researcher

The researcher is a senior social worker with the public health oncology services in Malta, thereby placing the researcher in a privileged position and part of the 'health services experience' which is the focus of this study. This reality implies a number of considerations:

Although the research could be seen by the participant as part of the health services experience, the work of the researcher is closely related to the accompaniment of the patient, the patients' family and the patients' support system in their treatment journey. Consequently, participants were naturally unperturbed by the experience of discussing their lived treatment experience with the researcher.

At the same time, as a consequence of the researcher being involved in patients' support system, this involvement could have led participants to confuse the role of the researcher with the role of a social worker. In order to avoid this confusion

of roles it had been decided from the start of the research that participants would not involve clients or ex-clients of the researcher.

Qualitative interviews necessitate extensive competence from the researcher turned interviewer. Many clinicians, particularly in the psychosocial field are already attuned to carrying out such interviews, maintaining control of the interview, bearing in mind the aim of the interview itself, asking the right questions to obtain the requested information and showing the appropriate verbal and non-verbal feedback. Holstein and Gubrium (1995) talk about the 'active' interview emphasising that all interviews are collaborative works with the interviewer eliciting different aspects of the interviewee's 'stock of knowledge'. A skilled interviewer supports the interviewee to "explicate how knowledge concerning (the) topic is narratively constructed" (Holstein & Gubrium, p. 56). The researcher being an experienced social worker provided a know how in conducting interviews which enabled the interviews to be a natural space for the participants to speak comfortably about their individual stories. The researcher confidently added appropriate questions on the lines of the research, as well as on where the participant was taking the interview. Such relationship created an extremely rich environment. For the researcher, the interviews were a confirmation that the patients turned participants are the experts of their experience.

3.5.1 Reflexivity

Being a researcher involved in the area being researched begets the notion of reflexivity. Working in the same area of study one does not escape from the consequence of that position. The concept of reflexivity as a researcher involves an on-going process of mutual shaping between the researcher and the research.

There is a “whole-person development of the researcher” (Attia & Edge, 2017) which adds enhancement to the research itself. Reflexivity comprises two interrelated elements: prospective and retrospective reflexivity; prospective reflexivity focuses on the effect of the researcher on the research, with Mann (2016) describing such reflexivity as focused on the self, “recognises mutual shaping, reciprocity and bi-directionality, and that interaction is context-dependent and context renewing” (Mann, p. 2). In social research, Davies (1999) beliefs that reflexivity “at its most immediately obvious level refers to the way in which the products of research are affected by the personnel and process of doing research” (p. 4). The researcher’s hermeneutic reflexivity is referred to by Finlay (2008) as a constant reductive-reflexive dance between restricting preconceptions interfering, and at the same time being utilised reflexively as a source of insight.

3.6 Conclusion

The research philosophy influencing the research design of the IPA method together with a methodological map of the research process was presented in this chapter. Within the limitations of the methodology chosen, it is recognised that IPA as a research tool provides a unique process to understand and interpret cancer patients’ experience of their treatment journey. The experiences are summarised, presented, analysed and discussed in the following chapter.

Chapter Four: Findings, Interpretations and Discussion

This chapter presents this study's participants' lived experiences of their contact, interactions and exchanges with the public health services in Malta through their cancer treatment and care journey. Following a brief introduction to the six participants of the study, the findings emanating from the interviews are presented, interpreted and discussed. The chapter is structured according to the themes derived from the data.

4.1 Participant Profiles

In the unique narratives of the participants, some context to the participants themselves is needed to understand their particular experience. The profiles that are presented are detailed enough to clasp their distinctiveness while keeping their anonymity intact.

Participant 1, Alex, is a male in his forties who, after experiencing sharp pain, was linked to the public health system via a private clinic and fast-tracked for a gastric operation. While recovering he understood that another operation might be necessary as well as chemotherapy. The link with the Oncology Centre (OC) happened a month and a half after diagnosis with news of chemotherapy leaving participant and his wife in a state of shock. At the time of interview, the intense and long cycles of therapy are over, and participant is in the follow-up phase on an out-patient basis at the OC. Alex is a husband and father of a son in his twenties. Throughout his illness he managed to keep his job as an employee

with a private company in the service industry. His wife, Alexandra, was present for the interview and participated in the discussion.

Participant 2, Pat, is a female in her fifties diagnosed with breast cancer in her late forties. Her link with the public health system commenced much earlier for gynaecological related health issues. The diagnosis led to a mastectomy operation, with prior planning, followed by reconstruction, via what participant described, as a very supportive post-operative health support system. She attends OC for monitoring and at time of interview was experiencing fear once again due to a possible recurrence. Investigations were underway. Pat is married and has a son in his twenties. Pat kept attending work for the large part of her illness, working within the public educational system. Pat's husband, Patrick, was also present during interview and participated in the discussion.

Participant 3, Beth, is a married female in her forties who was exposed to the medical world in her teenage years when she was diagnosed with her first tumour. At that age she experienced the UK health system for a specific treatment not available via Malta's public health system. She was again in contact with the health system when, at age 45, she was diagnosed with an intestinal tumour and has been on chemotherapy treatment ever since. The past three years have been characterised by hospital visits, treatments and frequent hospital admissions with an exposure to most wards in MDH and the OC. Beth had to resign from work due to the impact of the illness.

Participant 4, Henry, is a male in his sixties who started being exposed to the public health services over 10 years ago, first for orthopaedic problems and then loss of sensation, followed by an oncology diagnosis when his vision was being impacted due to a head tumour. He had to stop his working life prematurely, with

his days revolving around hospital appointments and interventions, the latest contact being with the OC. Henry is a spouse and a father to three children, now all above 18 years of age.

Participant 5, Thomas, is a male in his early forties with a recent short exposure to the public health services after being diagnosed with an Ear, Nose and Throat (ENT) tumour during the preceding year. He was used to sports injuries; however, the recent diagnosis, when appointment was seen as just a routine visit, as well as the treatment regime, proved the most challenging for his family and life routine. Thomas was exposed to the links of specialisations between the health services of MDH and the OC. He is married and father of two children under ten years of age. He and his wife, Maggie kept attending their office-based work within the private industry. An additional interview was carried out with Maggie.

Participant 6, Jill, is a female in her forties who over the past year and a half has had a whirlwind of health services' exposure, having undergone two operations, and radiotherapy treatment. The medical interventions for a kidney and a breast cancer have been life changing from all counts, particularly from the medical side. Her links with the health services are ongoing within the different specialised services at MDH and the OC; at the time of interview primarily on an out-patient basis. She is a spouse and mother of two girls in their 20's. From early on in her cancer journey she had to stop working as the nature of her work involved physical hands-on work. Jill has not as yet returned to formal work.

4.2 Five Superordinate Themes

Five main themes were identified from the detailed analysis of the interviews. These five themes are the end result of an analysis that identified 22 themes, whereby related and similar themes were grouped into a structure of superordinate themes. The five superordinate themes grouping the 22 themes identified in the analysis are:

1. Positive treatment experience
2. Overcoming identified service limitations
3. Humanity of care
4. Centrality of support
5. Burden of treatment

The 22 themes making up the five superordinate themes depict the researcher's interpretations of the participants' inimitable lived experience of the public health services within each participant's unique life context. The structure of themes developed from the analyses of the data does not reduce the importance of differences in meanings reflected in the participants experiences, as illustrated by the participants' verbatim narratives (Reid, Flowers, & Larkin, 2005; Smith, 2004).

Although the five themes are presented as separate topics, they are strongly intertwined as we shall see in the subsequent analysis. Table 1 below (p. 62) summarises the five main themes that emerged from the analyses of the data collated together with their respective sub-themes.

Table 1: Structure of Themes Framework

Superordinate Theme	Theme
1. Positive treatment experience	1. Perception of high standards in provision of public health services
	2. Significance of personalisation of services
	3. Sense of gratitude for public service provision
	4. Waiting time considered an accepted feature of public health service provision
2. Overcoming identified service limitations	5. Getting the logistics right can make significant constructive difference for patients
	6. Access to information on cancer treatment journey
	7. Psychosocial services' reach out to service users
	8. Fragmentation in health information system
	9. Distressing protocols for Palliative Patients
3. Humanity of Care	10. Centrality of breaking "Bad News"
	11. Impact of patients' interaction with health staff
	12. Handle with care!
4. Centrality of Support	13. Significant contribution of wider support network
	14. Employment system's support a critical factor for patients
	15. Health Literacy as a central fulcrum of service reach for patients
5. Burden of Treatment	16. Start of cancer journey conditions patients' burden of treatment
	17. Loss of Control
	18. Anxiety build up for tests and appointment days
	19. Anxiety build up for treatment patient has to undergo
	20. Traumatic illness journey
	21. Wider impact of treatment
	22. Coping response as a mediating factor

4.3 Positive Treatment Experience

Cancer patients frequently describe their experience of the oncology public health services in positive terms. This optimistic appraisal appears to reflect a reality beyond the impressions of cancer patients who might not know any better, considering that a number of areas for potential organisational improvement were also identified. In analysing this general positive experience, it is necessary to factor in the good health literacy of the participants (Halverson et al., 2015). Increased health literacy has been shown to contribute positively to health-related quality of life among cancer patients (Halverson et al.). The main factors comprising this general positive experience are described in the themes below.

4.3.1 Perceptions of high standards in provision of public health services

To different degrees, the six participants experienced their treatment as partaking from public health services of high standards. Participants were trusting of the health service provision and the professional staff that operate them. The common factor amongst all of the participants was the contact with the OC whose service provision was described as excellent by Alex.

(See Appendix F with each Q link to Maltese verbatim quotes).

> Alex: "I only have one word to describe the service – excellent." (Q1)

Henry and Alex both voiced the benefit of a specialised centre for oncology:

> Henry: "Here (OC) because there is less influx of people like there is at MDH, here you feel calmer, in the sense that there is staff to assist you." (Q2)

Alex "For me I was in the best hospital that I have ever come across and I shall explain why as a service it was impeccable and I give it the highest score, in terms of treatment I believe they tried to give me the best treatment that presently exists in the world". (Q3)

Henry experienced smooth links between different specialist consultants, same as Alex. What could have been a major source of apprehension and fear when a new tumour was diagnosed, was taken care of by his consultant's explanation on how the referral to another consultant was to take place

Henry: "And he told me 'we shall be working as a team, meaning I will not be abandoning you. Your main consultant will be him' [the oncologist]." (Q4)

Participants communicated their reassurance that they were receiving the best of treatment with an understanding that if more is needed to be done the consultants would link them to treatment overseas. Pat said she is doubtful of a better service had she to be taking treatment in another country.

Henry "We are very advanced here" (referring to MDH and the OC). (Q5)

4.3.2 Significance of personalisation of services

Participants highly valued being treated as individuals and not seen as "yet another patient". This approach was echoed for the service provision at the OC and included expressed words of appreciation for being treated as a person by the oncologists, and their medical teams.

Alex's wife cherished her husband being treated as a human being and not just as "an object" by the consultant "as most doctors do, you are just a number". This family felt they could keep in touch with the treatment ward where the staff were

a phone call away to reply to their queries concerning side effects, and that link made a significant difference in this family's management of the cancer journey. Previous research has shown the difference a link makes when a patient is going through difficult times during the illness (Grassi et al., 2017).

For Pat the approach the staff had upon commencement of her medical investigations immediately made her feel reassured no matter the interventions she had to face:

> Pat: "The way they talk to you makes you feel like you've known them all along, you are not a number, they're very caring, very caring." (Q6)

Pat explained that thanks to the approachable staff she felt particularly comfortable and, in spite of having to face a mastectomy, she surpassed even the fear of pain. The patient's experience of feeling special, in the context of the difficult cancer treatment journey, reflected the personalisation of services experienced, each according to one's particular life experience or context. Referring to her oncologist, one of the participants used a simple, though powerful metaphor:

> Beth: "She is like my mummy, she takes care of me "(referring to the oncologist). (Q7)

In Beth's context, the words she used is a value laden image, considering that Beth's mother is always at her side, fully involved in her daughter's treatment, both when together they spent a year overseas for treatment, and in the past three years of Beth's more recent diagnosis. It was evident during the interview that her mother's place was special; thus, for Beth to use the same concept and

equate the oncologist to her mother shows the indelible mark the individualised relationship has left on Beth.

The critical importance of the relationship built with the medical profession within the acute health systems further reflected the significance of the personalisation of services (Bureau of Health Information, 2015):

> Henry: "You let go in the questions you put to him and he puts to you … not the fear that you are in front of a consultant and feel overwhelmed." (Q8)

Thomas portrayed a reflection on the impact of the illness journey and the importance of a personalised system of care, which for someone coming from a business background, highlighted a 'customer focused' approach:

> Thomas: "If the system does not allow you to do certain things it will break you." (Q9)

Thomas's wife tied the individualised service to a certain element of reassurance that can be given when specific patient's results are known to consultants, such as blood results showing a localised tumour.

4.3.3 Sense of gratitude for public service provision

Five out of six participants pronounced a sense of gratitude for the provision of the public health services they had received throughout their treatment journey. For most of the participants interviewed (four out of six) the experience of the health services, particularly the acute care services, has been an extensive one of three years plus. This sense of gratitude was not contingent on a good prognosis or a cure for one's illness. Even for participants with poor prognosis and full awareness that no cure was available, the sense of gratitude prevailed:

Beth: "I feel lucky to have such services that make my life so much easier". (Q10)

Jill had experienced a costly private sector reality for a number of investigative appointments she carried out. Using more public health services throughout her operations, rehabilitation and radiotherapy, she expressed gratitude for availability of the treatment services she needed, as well as for the personal attention she found from professionals she encountered in different hospital services:

Jill: "Better not away from my family, I remained here in Malta eh? I really appreciated a lot that I remained in Malta." (Q11)

4.3.4 Waiting time considered an accepted feature of public health service provision

Generally long waiting times generate complaints. Contrary to what is expected the six participants in this study took such waiting as an accepted feature of the public health service and no complaints were forthcoming. Alex excused the waiting as not dependant on the professionals, and everybody is very busy: "loaded with work".

Pat accepts times of appointments at any time they are given and

Pat: "I never comment on how long we have to wait." (Q12)

with an acknowledgement that there has been an improvement in the waiting time for appointments, and in the keeping to appointment times at MDH in recent months.

Beth has adapted so much to waiting times that she accepts needing to dedicate a day to an appointment:

> Beth: "I didn't use to bother (with hospital appointments). I say to myself that we have a day there." (Q13)

Henry described the waiting time from the diagnosis at MDH to the OC as nothing to write home about:

> Henry: "Not much. Not much, meaning months only. Maybe two months? There wasn't a long period of time." (Q14)

The acceptance of waiting time was said when both Henry and Jill were not experiencing any discomfort.

Maggie actually quoted a phrase the nurses used with patients, that in hospital you know when you arrive but you do not know when you leave! In her case Maggie, mother to two young children, without complaining for the long wait, did highlight the logistical nightmare such long waits have on the patients' other world, out of the hospital realm.

4.4 Overcoming identified service limitations

The participants' extensive involvement with the public oncology health services highlighted the centrality of effective communication. Communication was highlighted as one of the essential tools in participants' health services experience, contributing significantly to the provision of high standard patient care and person satisfaction. Improving the medical team's ability to communicate effectively with the cancer patient and vice versa emerged as a critical factor for enhancing the patients' treatment experience by enabling them to understand

information critical to their treatment choices, and for their recovery (All.Can International, 2019; Bureau of Health Information, 2015).

4.4.1 Getting the logistics right can make significant constructive difference for patients

There are practical considerations that also contribute to the nature of the treatment experience. Wagstaff and McIntyre (2017) state that to gain some normality an oncology patient needs to be extremely organised. Participants reflected on some aspects within the heath system that make big differences. The combination of appointments, which would result in less time used in being reminded of being a patient at MDH, was mentioned by all participants once topic was explored:

> Pat: "It would be very good if one would have the blood test and the other tests in same morning." (Q15)

Such frequent appointments become concerning when, for the most part, there is a build-up of anxiety and fear with every hospital appointment.

> Pat: "For example, even last week I had an appointment on Tuesday, it was at oncology and Wednesday I had an appointment with the surgeon at MDH. I was anxious at having to go twice in a row to hospital." (Q16)

Better logistics for better management of treatment is reflected in what Beth did. She went around the frequent hospital appointments by asking for the earliest time available so that the significant person who accompanies her is still left with time for personal errands. It is interesting to note that in this case, the significant other accompanying Beth is her father who is retired. Still Beth acknowledges that her father has a life beyond her hospital appointments:

Beth: "I request the earliest (appointments) because of my daddy so that like that I do not keep him from taking care of other things, if he needs to." (Q17)

Henry daily starts his day by asking himself which hospital appointment he has; he states that he can hardly plan a private appointment outside the hospital system. Although Henry takes this reality in his stride, it is a significant reality he is living, day in, day out, a reality that reflects his cancer journey. For patients with Henry's treatment regime, a good system of transportation is vital and makes a huge difference for those who are unable to travel alone; otherwise the logistical nightmare is shifted to a significant other who, probably works, who needs to take time off from work and necessitates coordinating lifestyles to fit accordingly (Northouse et al., 2010). Henry highlighted the concerns of those patients, a high percentage of whom are elderly, who need to attend for radiotherapy twice daily, proposing a day hospital type solution to accommodate those who otherwise would not manage the two visits per day, five days a week. Jill does not drive and is unable to use the bus system, so appointments are described as a headache. Still she tries her best to attend at the time she is given. Looking back now that treatment is over, she acknowledges how many people she roped in from her family and extended family in order to keep the hospital appointments, demands that she understands were necessary, however challenging, but which also could have been improved with better appointments' coordination:

Jill: "Yes better that way, for me much better not needing to find someone to get you to hospital. Those who work cannot stay coming and going from work to take someone for a hospital appointment." (Q18)

When the participants were asked to focus on actual logistics of treatment they did recognise aspects that affect them and prefer to be different to what is actually taking place, and this shows a variation to the theme of waiting time as an accepted feature of health care provision where statements like “it doesn’t bother me” were said. The underlying message researcher understood was that the patients appreciate the service provision and are ready to wait; however, they do prefer a better system with a less time-consuming treatment path.

Thomas spoke about the new hospital system, the new appointment mobile application. He sees it as a good app that assists in reminding patients about their coming appointments. However, he sees it as needing fine-tuning, as apart from receiving other people’s appointments by mistake, it is a nuisance for same appointment reminder to be sent multiple times. Frequent reminders risk increasing the burden of treatment, the opposite effect to what they were intentionally created for.

> Thomas: “They blasted my mobile with appointment messages as I have the app and I receive messages and I receive messages all the time. So I’ll have an appointment, sometimes I receive 4 messages for the same appointment.” (Q19)

Now visualise the above happening with someone who has regular appointments, as is the case with Henry or practically all of the interviewed participants in this study. The app sure transforms into an annoying reminder of one’s medical status (May et al., 2009) and further deprives the cancer patient any resemblance of normality (Wagstaff & McIntyre, 2017).

Beth raised issues of when health policies create obstacles for access to specific treatments. For the individual who, through no fault of his/her own, has been

diagnosed with a tumour that is located in a different part of the body to that included in policy, and therefore access to the same treatment does not fall within the standard medical protocols, it is unjust as a patient to be told that that same treatment is not available for you, particularly when the diagnosis has occurred at a young age. The health system needs to have a window of flexibility for particular circumstances to be evaluated on their own merits. Beth, who had been diagnosed twice in her young life with two challenging tumours, had to struggle even more to stop herself from feeling the victim of a health system (Wagstaff & McIntyre, 2017). The implication of being excluded within such a protocol meant a cost of thousands of euros for Beth's family, even with charitably support. In fact :

> Beth: (sighing) "I had to buy it (referring to Avastin). I had to lump it! When (oncologist) told my mother, mum said 'Oh my 30 years ago there was no Puttinu (Cancer NGO) to support us (in the UK), and now we will have to buy it!" (Q20)

4.4.2 Access to information on cancer treatment journey

Interviews with all participants showed the critical importance of information for patients and their significant others (Sainio et al., 2001). The significance of such information at the right time was especially recognised when it went missing (All.Can International, 2019; Bureau of Health Information, 2015).

Pat reflected on her anxiety as a result of her most recent appointment bringing up a query about a possible relapse, triggering worry of the unknown and needing to know an appointment date and an investigation process. Pat has already gone through such processes; however, the new situation re-triggers a lot of questions and fear.

Following an operation at MDH, Alex was linked to the OC for what he thought was a ‘formality’, understanding that his type of cancer had been treated through an operation. At his OP appointment at the OC, Alex was informed that post operation he required twenty sessions of chemotherapy cycles as an inpatient, five nights per cycle. Consequently, Alex and Alexandra were shocked and devastated, both bursting into tears upon entering for orientation at the chemotherapy ward. Alex experienced being ‘betrayed’ by the system. At such difficult moments research shows that what has been told to patients needs to be checked repeatedly, given the anxious moments the family would be experiencing (All.Can International, 2019; Sainio et al., 2001).

In Thomas’s case, rather than misguided information, he experienced incomplete information and significant information gaps on his treatment process. Had the information been forthcoming in a systematic way, it would have lessened the questioning, the anxiety, the racing to and fro, particularly for the wife.

> Maggie: “When he used the word ‘urgent’ it stuck with me that it’s a case that can’t wait and I freaked out.” (Q21)

Both Thomas and his wife Maggie, reflecting on the treatment experience, interpreted their anxieties as having been negatively affected by the absence of a clear explanation of the treatment process that needs to take its course.

> Thomas: “Had I been told that there is a process of 4 weeks which needs to happen and you cannot do it before the 4 weeks .. If you can reason with the information given, you say so there is a process that the system needs to go through … and I cannot tell him to do it at the end of the month so I get it over and done with, so I get to know what there is and there isn’t.” (Q22)

This led to Thomas and Maggie proposing an information link be set up between the professionals at the OC and the patients braving the cancer journey, via which patients' queries can be answered even after office hours and on weekends, in order to facilitate information and reduction in patients' distress (Bureau of Health Information, 2015).

4.4.3 Psychosocial services' outreach to service users

In the area of chronic illness, research on breaking bad news highlights the importance of psychosocial support services (Caruso, Nanni, Riba, Sabato & Grassi, 2017). Such need was verbalised mainly in two of the interviews, although all participants acknowledged an initial shock upon hearing a diagnosis or medical results. Jill was under the care of a psychiatrist having suffered a post-partum depression eighteen years prior. Having such information in her file about her vulnerability, a personalised system would build a support system around her to convey the kidney and breast cancer diagnosis. Jill interpreted as helpful the fact that she was already taking anti-depressant drugs when receiving the news about the kidney's diagnosis, a coincidental fact without which her outlook would have deteriorated even further (All.Can International, 2019). The psychiatric follow up is ongoing and Jill found such appointments to be supportive and beneficial.

Thomas described two consequences upon being told the unexpected at the ENT out-patient visit: the shock his wife, and to a smaller extent, he experienced; and the visible discomfort and uneasiness of the staff delivering the bad news on seeing how upset they were. At that point of diagnosis, the professionals offered the psychosocial services to the couple; however, such an offer was ill-timed and

interpreted negatively. Maggie, who described this appointment as a catastrophic blow, further explained how the links of support that were offered included an organisation (Hospice, an NGO) that for the lay person is known to support cancer patients with high demands who are possibly dying, further intensifying her shock. At the point that the services were offered Maggie and Thomas were still lost with the 'bad news' that had been given. In hindsight, reflecting on support services during the interview, Maggie said that had the psychosocial services been offered to her after the initial shock, or some reaching out occurred from the services themselves when her husband had commenced treatment at the OC, she would have accepted the support, and possibly been narrating a different story at the end of the treatment journey, given that Maggie perceived herself as having carried a heavy burden on her own (Nolan, 2003; Grassi et al., 2017).

> Maggie: "You would be here waiting ... and you ask 'How did I end up here? And you start crying and you start feeling that you are all alone and it is in those moments where you need the help." (Q23)

Maggie's and Thomas's experience of being offered psychosocial services highlight the reality that an offer of help can also be interpreted as an indicator of how grave a situation is, the 'if I am being offered help then something is really wrong with me' type of reasoning. Overcoming this limitation is only possible through the sensitisation of the treatment process to the particular and unique needs of the individual. Ensuring that cancer patients do not feel alone in their treatment journey cannot be achieved by simple referrals to psychosocial services (All.Can International, 2019).

4.4.4 Fragmentation in health information system

Alex waited for over a month and a half between the time of the operation at MDH and the first contact with the oncologist. This time is not completely wasted as the patient would likely be recovering from an operation and regaining strength to take up the chemotherapy challenge. However, the lack of communication between MDH and OC transformed Alex's wait to a meaningless delay and a source of anxiety. At times, the information is absent because the patient's medical file is missing or important documentation is misplaced, as experienced by Pat. The hospital IT medical set up (CPAS and ISoft) has reduced such occurrence and facilitates up to date links between the different services in hospital; however participants still brought this concern up as it still happens.

The gap in health systems' information was felt by Thomas where information regarding oncology related matters was more forthcoming from the ENT section at MDH than from OC. The professional from the ENT section proved to be a key link for Thomas and Maggie during Thomas's treatment journey and beyond; having such a link had a significant positive impact on Thomas's management of the side effects of treatment and also on his wife's mental well-being, particularly during the treatment phase. Maggie had numerous questions which she sought answers for; however, had it not been for this ENT link, the anxiety that all those unanswered questions would have built up in her would have made management of the treatment untenable. Thomas felt reassured, once he was given clear information, that prior to six weeks he could not do anything with regards to commencement of treatment. More precise information in line to the individual's specific pathway is vital for the scale to tip towards better management and not

towards overwhelmingness (All.Can International, 2019; Bureau of Health Information, 2015).

Beth experienced the worst nightmare as a consequence of a health services silo mentality. She had been admitted to the gynaecology ward with a suspected, but still unconfirmed, tumour. The wait for investigations is already tough, let alone when a nurse approaches the patient almost scolding her for what she is experiencing, rather than reassuring patient. The lack of sensitivity could be per chance, because of the attitude of individual nurses, such as in this case. However, it could also reflect the lack of knowledge and sensitivity by staff on challenging illnesses, such as cancer, with the intricate pain management it involves (All.Can International, 2019; Bureau of Health Information, 2015).

4.4.5 Distressing protocols for palliative patients

A significant distressor identified in this study that is linked to gaps in health systems' information, particularly at MDH, is the admission issues of oncology patients. Patients are admitted at the Admissions and Emergency Department (A&E) when they are very sick and require interventions at an acute care hospital. Oncology patients are informed prior to their first day of treatment that they are to avoid crowded places to reduce infections given that during treatment their immunity is very low, and to rush to MDH should they have fever. The A&E is not informed of such patients and generally, in an A&E admission, oncology patients wait with the rest of the individuals at the A&E, are subjected to all regular A&E investigations, and then admitted to any MDH ward. No doubt, the A&E dimension of a cancer patient's treatment journey is negative on several counts:

Beth: "At emergency it is true they give you the full service and they do tests for every part of your body just like in the beginning. Now the last time I went it was even better as they did not have access to my file from the Emergency (sarcastic) so they had to stay asking me (the patient) what I took and what I had not taken, my history from the start." (Q24)

Beth's statement is concerning as the information that is being relied on at an A&E admission reflects an individual who at that point in time is a patient in an emergency state, compounded by a deteriorating cancer illness. Beth stated that she learnt to insist with the admitting doctors at A&E that they link with her oncologist. Beth's insistence highlight the necessary process irrespective of whether or not patient insists for it, more so if the admission is related to oncology matters. Because of Beth's frequent admissions to MDH, A&E consultants sought to implement a better system by allocating her to one medical consultant who linked with the oncologist:

Beth: "At A&E they do not know, nor where I should be admitted. But then I started telling them to link with my oncologist and they adopted that process." (Q25)

Henry, who has needed to call an ambulance frequently, noted the difference the ambulance makes in the waiting time and attention given.

The distressing protocol at A&E for palliative patients triggers fear in oncology patients as they have no guarantee whether their real need for a single room, because of zero immunity, will be met, given the high demands on the beds at MDH. There is a solution which cancer patients readily identify:

Beth: "I have been in every ward [at MDH] … with a larger OC … we would not need to go to MDH for our needs." (Q26)

4.5 Humanity of Care

The beginning of the participants' journey of cancer treatment marked them with a clear new identity: they were now cancer patients, living with cancer, with all the connotations it involved. Right from the start, participants struggled not to begin losing their individuality. The serious illness they faced was clearly a life-changing event with the risk of losing one's sense of security, sense of purpose, sense of belonging, sense of identity, and one's sense of personal competence. Central to addressing this critical factor of the cancer treatment journey is the human dimension of the health care services, or the humanity of care. Medicine, with all its advancements, still demands a humanity of care if the individual is to be the focus of the illness and treatment (All.Can International, 2019; Black & Jenkinson, 2009; Bureau of Health Information, 2015).

4.5.1 Centrality of breaking "Bad News"

Alex uses the word "blanked out" and "I did not understand anything", to describe the time he was told about his cancer diagnosis. He was in extreme shock the moment he was told the news by the surgeon, so much so that he felt the urgent need to call his wife in order for her to hear the information directly from the surgeon. Pat's husband, Patrick, described the shock he experienced, emphasising that it was almost more than the wife's, when Pat's diagnosis was confirmed.

> Patrick "When we left the hospital we went straight to the doctor, my wife went in and I stayed outside calling my siblings. I had a big shock, big shock, you start thinking lots of things, not knowing what is going on, unlike her (the wife)." (Q27)

Jill received a phone call asking her to go to OP on the morrow because the doctor needed to talk to her. This phone call was for Jill the herald of her death sentence; the hours until appointment time, the following day, felt like eternity. Rightly so, Jill asked whether a phone call that makes a patient to suspect the worst kind of scenarios should be the system used to initiate the breaking of bad news?

Beth, upon going to a doctor's clinic with flu like symptoms, was told to rush to hospital; her GP had found a large mass. Beth pronounces that "a bomb fell" and being alone at the clinic, she had to handle the exploded bomb all alone:

> Beth: "At that moment I was all alone which means that the bomb exploded while I was all alone. Anyway, then I came to emergency and I found myself at gynae." (Q28)

Even when the bad news was given without any further aggravations, it was still experienced as "very shocking":

> Maggie: "We had a very good service; however the way news is given the first time round was shocking, very shocking indeed." (Q29)

Maggie was so shocked at the point of hearing the news that she fears that if someone has the tendency to suffer from heart problems one risks experiencing too big a shock (Grassi et al., 2017). Additionally, patients experience disbelief, blankness and general lack of understanding.

> Maggie: "The specialists just tell you that we carried out a biopsy which resulted cancerous. At that point you have no reaction, you do not know how to respond, and you begin to ask whether what they are saying to you is true or not?" (Q30)

4.5.2 Impact of interaction with health staff

Working in a hospital setting staff are faced with constant difficult situations. At the same time the patients have too much on their plate to receive additional aggravation from staff who are meant to be there to support them (Black, 2018). Beth narrates experiences gone through at the beginning of her diagnosis which still generate agitation three years on. She had a canula which was causing a lot of pain when she was at MDH awaiting results of primary investigations. The reaction a particular nurse gave her was one of blame:

> Beth: "And she told me, "the vein is good, the canula is inserted well. How come you only spoke now? The night doctor has just left" .. and she did not want to remove it for me." (Q31)

Alex was also agitated recounting a negative incident that happened while he was in the chemotherapy ward, unrelated to his treatment complications which, however, seems to have distressed him more. Two years on he had this to say:

> Alex: "It affected me a lot, and even my wife, and I got worked up about it even more as the incident brought my wife in tears, so more and more." (Q32)

In a continuum of care, high standards of care and sensitivity are the hallmark of services that leave a positive mark on patients (Black, 2018). The negative impact of a distressing interaction with health staff is as notable as the positive bearing of comforting interactions (Bureau of Health Information, 2015):

> Pat: "There is a nurse who used to call me, very sweet, and after the operation she came near me and stayed talking to me. I found a lot, and a lot of support." (Q33)

4.5.3 Handle with care!

Jill speaks of “gently does it”, about staff communicating with them as patients. She says the same thing about patients communicating with staff. Such gentleness takes the patient-staff relationship far (Nolan, 2003). Henry adds that for every patient his or her own situation is the 100% of their treatment experience, and the patient-staff relationship needs to acknowledge that fact (Arman, Rehnesfeldt, Lindholm, Hamrin, & Eriksson, 2004). Consequently, the patient-staff relationship requires unlimited sensitivity, a sensitivity that influences positively the cancer patient’s treatment journey:

> Alex: “Exactly as no matter how much you know, in front of you there is a fragile human being because had you seen me during the treatment phase and you see me now you say I am a completely different person, you know how often I cried in hospital!” (Q34)
>
> Maggie: “It is true that they (doctors) give treatment etc but they are not the ones going through the illness just like you are. The consultant leaves the clinic, forgets you and meets someone else, but for you that word of his is critical.” (Q35)
>
> Pat: “As a link with hospital it is good when you have a doctor who is talking to you (the patient) and he is explaining in a calm manner … and it is bad … when you find someone who is considering you just another patient. I want them to talk to me gently as I am a bit sensitive.”(Q36)

4.6 Centrality of support

Another critical factor in the participants’ cancer treatment journey was the centrality of the different layers and dimensions of support that sustained them throughout. In the best-case scenarios the health services recognised the

informal and formal support networks as partners in the treatment journey. The support dimension of one's cancer treatment was highly enhanced when factoring in the person's resilience (Anderson, 2019; Black, 2018). All six participants in this study acknowledged the incredible difference the support they had made during their treatment journey.

4.6.1 Significant contribution of wider support network

The support received by participants was described as "family means a lot"; "enormous help"; "once you start finding so much assistance you almost don't know where to start"; "support from family is positive; "I consider myself lucky"; "found massive support"; "much appreciated"; "a big thank you"; "the support puts your mind at rest"; "thank God for family and other support".

The impact of the support network led Alex to state: "I used to believe that we will overcome it, we shall overcome it", meaning the illness".

> Pat: "I never doubted that my family love me, I mean my husband, my son, my siblings, my brother in law, but from this experience I saw the amount of love they have for me, I felt it and I said 'they really love me' ... and they come every day, and they call. A problem shared is a problem halved" (Q37)

To the question what helped her cope Jill immediately replied:

> Jill:: "My family, I had my husband and I had my children who I really respect." (Q38)

Jill was accompanied for her medical appointments by her 73-year-old mother who insisted to be there for her daughter; a mother who wanted to physically accompany her daughter in such difficult moments, and age did not deter her!

Beth also had the experience of having her mother, a pillar in her life, assisting her to find the strength to handle the tough news and even to adjust to the traumatic illness and its side effects;

> Beth: "My mother is like that .. she comes to hospital and brings me food ... she will not put herself in a corner and stay crying." (Q39)

Thomas cannot imagine someone going through such an illness without support. His comments are interesting given that prior to his illness his nuclear family's frame of mind was to manage independently. In less than six months following the diagnosis, the reality had completely changed:

> Thomas: "We always kept back (referring to their parents' request to have the children at them). Then this illness changed everything as my parents ended up cooking for me, taking the children to school daily, at times after school they kept the children at them, with sleepovers too, things that we did not use to do before as we used to say 'they are our children and we bring them up." (Q40)

The wider support was appreciated, even from other formal services including psychosocial services and any practical support that could be provided (Grassi et al., 2017).

4.6.2 Employment system's support a critical factor

Of particular importance for participants and their families was the employment dimension of the support they received, whether to allow patient to work through the difficult treatment scheduled or to maintain an income during long periods of illness. "The good thing about it (the illness) is the support that you have"

Thomas's argued. He used the words below to describe the difference employment system's support leaves on a patient going through an illness.

> Thomas: "I was told from work to do what I wanted, meaning see what you need and thus that is already a plus." (Q41)

The support significant others had from their respective networks, particularly work flexibility, was considered a critical factor in the cancer treatment journey. Maggie had absolute support from her place of work too. Jill was very grateful for the support her children found from their place of work, adding that one of the managers at her daughter's employment had been exposed to cancer treatment in the family and this aided understanding and cooperation. Thomas summed the issue as follows:

> Thomas: "So you have support from the two places of work, you have support from the parents, I had support from the sister in law cooking ... as long as you have support in this world, life will not remain so normal, however you will not find yourself in so much danger." (Q42)

4.6.3 Health literacy as a central fulcrum of service

Interviewing and analysing these participants' wealth of experience of health services, the researcher came to the realisation that there are a personality's inner strengths that play a significant part in the interplay with the services, treatment and health processes. Inner strengths are what one is born with, however the set ups encountered can either enhance or suffocate such strengths (Wasson & Coleman, 2014).

Beth asks how she could possibly have been diagnosed with yet another cancer, but her sigh is only for a second, ready to fight it a few pauses later.

Beth: "You say how could it be that I got it again? But then I gear up to fight it." (Q43)

In spite of his deteriorating health situations which have left him disabled and unable to progress with employment, Henry still sees himself as an important part of society, needing to be heard and with a lot yet to offer:

Henry: "There is something in you that keeps you believing that you are part of society. Although you have problems you still form part of society; not because of this problem I form only one sixth of society, no. I remain part of society where I can still do good, up to where I can get to, but I can still do it." (Q44)

Health literacy is also a function of one's resilience; it is circular (Jacobs et al., 2017):

Thomas: "I started my contact with the OC with the premise that I want to keep living, and I want to live a normal life. I never felt like a patient as I used to go there (for hospital interventions) like I was attending any other appointment." (Q45)

Research has shown that service users who participated in decision making have better problem-solving skills and used such skills more frequently (Degner & Sloan, 1992). Health confidence thus engages patients to improved management of their illness (Jacobs et al., 2017; Wasson & Coleman, 2014) while social work and other psychosocial services within health are challenged to bridge the existing gap between the formal health services and the patient's formal and informal support networks (Oliviere, 2001).

All the participants in this study demonstrated a high level of health literacy, a reality that gives rise to a fundamental question not addressed in this study: What is the cancer treatment experience for patients with low health literacy?

4.7 Burden of Treatment

Irrespective of their diagnosis, prognosis, treatment regime and treatment outcomes, cancer patients described the burden that the treatment journey meant for their life outside the patient role, and for the life of their families. Previous research has shown that a serious illness is like a stone that hits the still waters and causes disturbances in the shape of feelings, thoughts and reactions. It impacts relationships, challenges systems and the haemostasis (Bolen, 2007). The recognition of the burden of treatment for cancer patients is a critical factor in designing health services that are more responsive to the life situations of service users (All.Can International, 2019; Caruso et al., 2017).

4.7.1 Start of cancer journey conditions burden of treatment

Alex had everything explained to him prior to commencement of treatment by the consultant and the information session. The information was perceived as adequate for patient as it was kept simple and straight to the point; in such moments, medical staff's sensitivity is vital for the overwhelmed individuals they would have in front of them (Sainio et al., 2001).

Alex "First and foremost when the individual is going through something like this (a recent diagnosis) telling him a lot of information, or you tell him so or you give him a lot of papers is futile. You need to go straight to the point ... and tell him the exact information, when he is to come in, what he will be taking, experiencing etc in bullet form." (Q46)

Assessing what patients will be going through as they come in contact with the health services following the giving of bad news is exceptionally challenging as staff would not yet know the individuals in front of them. Additionally, the patient's reactions cannot always be the measuring stick on the weighting of the burden being faced (Wolf et al., 2017). Thomas recalled that on hearing the news of his cancer he turned very quiet. Others tend to look overwhelmed. However, the initial reaction cannot be the only yardstick by which to measure the individual's coping level (Grassi et al., 2017).

4.7.2 Loss of control

All participants in this study described a sensation of losing normality, the tough realisation of the fragility of their body not cooperating with their wishes, and too many reminders that they are patients of the health system (Wagstaff & McIntyre, 2017; Grassi et al., 2017).

Henry admits that these days his life does revolve around frequent hospital appointments, with a real need to attend to hospital appointments first, prior to any other life routines; "more in hospital than at home". Hospital appointments have become the centre of his life; an "incumbrance", ("skariġġ"), which he cannot do without, but at the same time is so grateful for.

The side effects of cancer treatment come with the shock of a life limiting journey, which, most hope, has an approximate six-month temporality.

> Alex: "The worst issue I had that really frustrated me ... was that I felt so drained, so much that there were times when I couldn't even hold a cup of tea in my hands ... especially when you consider that I was an independent healthy person ... and then all of a sudden for everything I need assistance, your reasoning starts playing games." (Q47)

Another aspect in the loss of control raised by participants is the frustration of not having one's voice heard. It gets more concerning when patients speak about their experiences of the effects of treatment (Sainio et al., 2001). Alex recounts how, had it not been for one particular doctor who saw the severity of the side effects he was experiencing and had been trying to tell staff about, he would have died.

Having faced a variety of doctors' approaches in his health journey, Henry refuses to give doctors full control over his life:

> Henry: "When the doctor tells me 'you have this, you have this and that, you shall feel this and this' ... afterwards I tell myself, 'I am my own doctor, I feel my own pains. I cannot feel yours, your source of pain. So all right the doctor is there, he will explain to you, he will show you the path of treatment that you are expected to pass from, so to speak. At the same time the road can be steered by yourself too." (Q48)

The loss of normality was nailed by Jill when she said that instead of going for a coffee she had to go to the OC for treatment, for weeks in a row!

4.7.3 Anxiety build up for tests and appointment days

Every contact with health services is a reminder of health issues. Appointments trigger a logistic headache and possible apprehension in the build-up for required medical tests and anxious expectations for results, emotions that all the participants faced (Grassi et al., 2017).

> Alex: "Every appointment for me has become a frightening experience. Why is it frightening? Because as much as I did not use to fear the hospital, I have become terrified of it, even just passing near it." (Q49)

Alex's anxiety included one fainting spell after another when the day for treatment drew nearer, also suffering from insomnia with the apprehension of another cycle.

> Pat: "The day prior to every appointment, irrespective of what the appointment is, I am always somewhat anxious, always, even if I know that there will not be major concerns, an appointment is always accompanied by a certain amount of fear." (Q50)

Jill expressed feeling troubled with every appointment she still has in hospital, while for Beth the build-up, during the three week period she had waiting for the appointment link between MDH and the OC "shattered" her. A long waiting period is a recipe for compounded anxiety, and, according also to Thomas, extremely "painful". Maggie, spent the five days waiting time prior to meeting the oncologist unable to sleep, fretting on the diagnosis (All.Can International, 2019; Wagstaff & McIntyre, 2017).

4.7.4 Anxiety build up for treatment patient has to undergo

Literature shows that cancer treatment is definitely burdensome, offering unwanted physical tests as well as mental challenges (Grassi et al., 2017). Jill described herself during her kidney operation as being in so much pain that "her brain stopped functioning", meaning she could not think. Maggie felt she had to be there accompanying her husband during chemotherapy just in case something seriously wrong happened; the journey described as "a very rough road". The treatment associated with cancer is a main source of patients' anxiety:

> Alex: "The words 'cancer and chemotherapy' are not something like the cleaning of teeth. A lot of toxins will enter your body, so to speak, and these toxins are meant to do you good, however there is no guarantee, as you know as much as I do, that there is a list of side effects felt. Meaning these kill some things in the body and they kill other things too." (Q51)

4.7.5 Traumatic illness journey

Maggie cannot get rid of the anxiety of the treatment experience her husband has undergone, even now that the treatment is finished, so much so that she believes she is now "sick with something". She was strong during the treatment phase managing the children, treatment logistics and work routine, and being there for her husband; however, post treatment she felt the impact of the illness "with a bang" (All.Can International, 2019; Grassi et al., 2017). On the other hand, Thomas's mother, at the point she was told the news of the diagnosis by the patient/son himself, showed different emotions at different phases of the bereavement process. She had lost a son in his teenage years, and such bad news took her back in time to other negative associations she had lived through. It is a fact that tough news triggers associations with past memories (Grassi et

al., 2017). Such knowledge of associations present challenges at the point of diagnosis as, with new cases at OP, there will still be a lot of unknown about the patient's life history and coping skills (Arman et al., 2004).

Henry sees his worst nightmare had he to become bedridden. Such a situation would shake all his positivity. Beth cries when she reflects about a high possibility of not enjoying her family for much longer given that the chemotherapy was stopped as it was not having the needed effect, with "no treatment" equals leaving the tumour "to grow out of control":

> Beth: "I am a fighter, however, doubtful moments come where one starts realising certain things." (Q52)

For the significant other it is a particularly harsh reality feeling helpless as to how they can assist, generally, with confusing directions from the patients themselves as they are going through this difficult treatment for the first time and have no clue how to face it any better (Mazanec et al., 2015).

> Beth: "My husband is having to be very patient. All the things I used to do now have to be done by him ... my husband does not show it but he worries. And at times he cried also with his siblings etc." (Q53)

Pat's husband explains the shock he experienced following his wife's diagnosis. He gets a lot of thoughts on how his life would be like had he lost his wife to cancer, however his wife is an encouragement for both of them.

For Alex the whole journey of cancer was traumatic for him, his wife and son. Alex faced life threatening side effects such as feet clamping and excessive tremors, so much so that the chemotherapy had to be stopped. This experience

left a tremendous impact on the family's morale, as well as lingering physical effects of the chemotherapy reaction.

4.7.6 Wider impact of treatment

Treatment left a wider impact on all six participants, be it an outlook on life, a change in routine, or some other aspect of living. Some participants found themselves challenged positively, triggered by the jolting illness experience (Baker et al., 2016). Jill felt that her family came closer during her illness with a greater appreciation of each other. Jill described that the most positive experience she faced as a patient was when her daughters, soon after all the treatment was finished, took her on a surprise visit overseas, her first trip abroad where a lot of family memories were collated. Even Alexandra described the illness as having gotten their family closer as there was a shift in what they now consider important; seeing patient healthy and being together became the most important things for them. Normal routine of work, home and leisure were appreciated prior to the diagnosis however:

> Alex: "These days it's as if someone opened your eyes and literally made you see a clearer picture." (Q54)

Henry strives to keep as independent as possible, although he already has to use a wheelchair, keeping appointments where he requires accompaniment to a minimum. These days he does not plan the morrow, having had to adapt to various health challenges. Maggie describes how her life has changed and such a change is irreversible.

Maggie: "Once the word 'cancer' is mentioned you will always have that question mark and that thought is a heavy toll to carry … you cannot feel good as you feel helpless." (Q55)

4.7.7 Coping response as a mediating factor

It is amazing how an individual's resilience is shown even in the worst scenarios faced. Participants' stories brought out initiatives they developed to cope with the treatment journey and beyond, particularly when they could comprehend and process the multiplicity of treatment related details they were presented with (Bolen, 2007).

Alex took a decision "to live, not to simply exist", with "keeping active" forming a decisive part of healing. Pat tries to see positivity in everything and to keep things to what they are; being available to assist others going through her similar illness situation. Beth believes that when one is feeling good, irrespective of the health status, he or she needs to make the best of it;

Beth: "Before when I was eating well, me and my mother (used to prepare) like a picnic. We get sandwiches, all the time eating and taking chemo at the same time ... we take things like this, even my mother." (Q56)

Henry does not look back, what's past is gone and finds strength in his sense of humour, laughing even about himself, not realising that he'll be dead once it happens! Henry strives to take the best from what is given:

Henry: "If you keep hitting your head there will come a point where it will tell you STOP." (Q57)

Thomas believes that his positive attitude to life has helped him through the challenges of treatment. He approached the whole cancer journey with an

attitude of “wanting to keep on living, living a normal life” with a set of instructions given by the consultant and the radiographers which he followed, seemingly coping by taking a distinctive sick role in seeking and obeying doctors’ orders:

> Thomas: “Tell me what needs to be done and I will follow (referring to the radiographer).” (Q58)

Maggie, on the other hand, was shaken by the news and lost her sense of security that had surrounded her up to the illness, believing she was in control of her life with her hard work. “Courage is everything” and that was the tool Thomas’s wife, unknowingly, used to face the challenges of the illness, which she never visualised she could ever cope with, believing she would die had she to face an illness in the family. Reflecting on the cancer treatment journey, she realised that she was stronger than she ever thought:

> Maggie: “It is true when you get to face it, you are right, you are stronger than you think.” (Q59)

Jill kept strong in the midst of bad news, minimised the problems, and developed an existential mantra to cope and forge ahead:

> Jill: “I have no choice except go on with life.” (Q60)

Participants in this research brought to the fore the setback of bad news and how disempowering a diagnosis can be. Bad news can disempower even members of the family in a way that their resilience is shuddered. Health services have a significant role to play, supporting cancer patients and their families through their extreme vulnerabilities, which, if not addressed are likely to disempower the cancer patient from taking an active role in one’s treatment. When services work closely with patients and their significant others outcomes can be improved by

supporting the patient's coping capability towards their own treatment journey (All.Can International, 2019; Bureau of Health Information, 2015).

4.8 Conclusion

This chapter opened a window on to the lives of six cancer patients as they struggled and journeyed through their treatment process, both supported and disrupted via hospital visits, interventions and contacts during their cancer trajectory and other health diagnoses. Participants' conversations with researcher brought out the uniqueness of their challenging experiences. In their uniqueness the narrated stories also had lots of common threads, which were grouped in five superordinate themes.

The complexity, variety and intensity portrayed in the lived experiences of cancer patients and their families during their illness and treatment bring to light the massive task for health services that aim to respond to service users' needs to enhance the treatment experience for both the users and the providers.

The findings of this study clearly show that participants were, at the same time, both appreciative and positive about their treatment journey while also fully cognisant of the many areas that can be addressed to enhance their journey as cancer patients and cancer survivors. Central to the treatment journey are two factors that have the potential of determining one's ability to cope with the illness and its difficult treatment regime. The humanity of care is recognised as a critical factor in the context of the extreme vulnerabilities resulting from the illness and its treatment. The humanity of care is further enhanced by the support that characterises the way various systems operating around the patient's life. These

two factors have a strong bearing on the burden of treatment that cancer patients and their families experience.

The pertinent question to ask at this point concerns the challenge on how to integrate the lived experience of cancer patients as health service users into the core of health care planning, service development, and delivery. The concluding chapter attempts to approach this question, within the limitations of the study design.

Chapter Five: Conclusion and Recommendations

In this brief concluding chapter, the challenge on how to integrate the lived experiences of cancer patients as health service users or co-producers in the core of health care planning, service development, and delivery is discussed within a critical appraisal of the study's strengths and limitations. Subsequent recommendations are correspondingly put forward.

This research project addressed the question of how cancer patients and their loved ones live their experience as consumers of health services during the illness, with a focus on factors in the structure and delivery of health services that directly impact the life of cancer patients and their support system. The idiographic approach taken in this study logically emphasises the uniqueness of each participant's experience. Such an approach risks rendering itself unworkable for health services planning, management and delivery because public health services have to cater for all. One may argue that it is not possible for public health services to meet the particular and specific needs of each patient, thereby adopting a highest common factor approach that disregards all those factors that are unique and not common.

The focus on the individual patient's experience suggests an alternative approach, one that recognises all the diverse factors that may pertain to different patients and works to develop systems, policies, and services that are capable of adapting themselves to these diverse factors. This approach is in line with Donabedian's (1992) insistence that any approach to quality assurance has to be relevant to patients in general but also to each patient in particular. Such an

approach recognises that the services' capability to recognise, address and respond to individual patient's needs ultimately benefits other patients who may be in similar situations and therefore improves the quality of the health services system itself.

5.1 Strengths and Limitations of the Study

In drawing any conclusion from this study, one has to bear in mind that the data is drawn from the lived experiences of six cancer patients as they journeyed with their illness through the treatment trajectory. Their experiences are at the same time unique and limited. For instance, they may not represent the experiences of patients who do not have the agency or social capital to work collaboratively with the health services system. Their experiences do not represent the distinct realities of other cancer patients such as children, youth, or older persons. Participants had different cancer diagnoses which also makes it difficult to generalise one patient's experience to another. Additionally, given the nature of IPA as a methodology, participants were selected on the basis that they had the cognitive ability to reflect on their experience and were able to communicate such reflection. Consequently, these limitations dictate that conclusions and recommendations drawn from this study are seen as a partial contribution to the overall perspective required for health services planning, management and delivery.

Notwithstanding the limitations outlined above, there is a usefulness to this study as it gave six cancer patients the opportunity to share their specific experiences of negotiating the health services through their cancer trajectory. The chosen methodology produced extensive narrations of six lived experiences of the

patients' interactions with health services in Malta, their health journey experiences, enabling idiographic portraits of individuals to develop through their stories. IPA lends itself for such depth to be uncovered.

Still the cancer patient's lived experiences depicted in this study are unassumingly a reflection and interpretation of six individual experiences of the health services in Malta; they cannot claim to represent the story of every cancer patient. The reflections presented in such research also have the risk of being essentially the researcher' assumptions and/or perceptions, and not the real thing, even though a lot of consideration was taken to limit such bias from occurring. Understandably, the orientation of this study works on the philosophical assumption that there is no one "real thing" and that the scope of research is to uncover different levels of realities depending on the diverse perspectives adopted. The perspective of this study involves the researcher's interpretations of the participants' construal of how they experienced the health services in Malta through their cancer journey. The language aspect of the research also has an interpretative element with some of the richness, accuracy, idiosyncrasy, and poignancy possibly having been weakened in the process of translating participants' Maltese narrations into the English language. The conclusions and recommendations drawn should be read within this perspective, with its strengths and limitations.

5.2 Key Conclusions

The key findings from the lived experience of cancer patients and their significant others as they interact with the public health services to receive cancer treatment portray a picture of patient realism. Participants had positive experiences of the

health services, while identifying service limitations and areas of process that require what Donabedian (1987) refers to as ongoing fine-tuning, “the process by which performance is periodically or continuously reviewed and, when found to be deficient, first modified and then monitored once again” (p. 81). Participants reflected on the need for a more humane approach when conveying bad news, and on the centrality of support, both familial and work related, for the management of the cancer treatment. Findings conveyed the burden of treatment experienced by cancer patients, by family and significant others.

The health services, primarily the acute care services, and notably the oncology services, were described as having good internal links and high standards of care. Health services were held at high esteem. It is interesting to frame this perception within the ‘small country phenomenon’ research: Is such perception conditioned by the lack of alternatives with which to draw comparisons? Participants experienced the treatment process as a lifeline, giving them a sense of security and purpose, striving for a balance between living life and managing the illness.

The general positive description of the health services was accompanied by a recognition of gaps in services and areas for service improvement. Situations where the missing links in the health systems’ information led to distressing experiences were spelt out by participants. Participants’ narratives related how they perceived better outcomes and management of their treatment experience when services worked closely with the family and other support networks. Better communication systems between MDH and the OC, particularly regarding admissions of palliative cancer patients, would raise standards of care and enable patients to experience a step up in their quality of life till the very end. Flexibility

and individualisation, when experienced, were praised and seen as critical tools to be developed further by the health system.

One particularly concerning area of care where the link between the different specialised services of care are failing miserably is at the A&E, especially in situations of patients who experience repeated admissions. For A&E, a new admission is a new case, with the consequential repeated tests and investigations. In addition to the costs involved in the numerous 'futile' investigations, it is also a costly system for the cancer patients who find themselves in a health structure and system processes that do not understand their situation and potentially increases their health risks. Narrated experiences by participants showed clearly that staff at the acute care hospital lacked knowledge in palliation systems of care. Such need is urgent particularly considering cancer as "our new normalcy". When countries like Malta are moving from one in four, to one in three, to one in two, cancer will be an "inevitability" (Mukherjee, 2011, p. 459).

In managing the burden of treatment, patients feared being alone in their treatment rollercoaster, valuing accompaniment, professionals to speak with, to hear them, to give them practical tips, and to help them cope – the humanity of care. The experience of being given the cancer diagnosis features as the crux of the cancer treatment experience. Participants remembered every emotional detail of the episode, but, in contrast, they were not able to understand what was being said to them, needing the significant other to ask questions of clarification on their behalf, feeling overwhelmed and speechless. Patients acknowledged their need for time and presence with patient and family at the breaking of bad news, and also for time alone to process what was happening. An overwhelming

shock experienced at the diagnosis stage disabled significant others from being able to support the newly diagnosed patient. Clearly, health services complicate matters for the patient, the patient's family, and for the health services themselves if the bad news is conveyed in a way that disempowers a family to the extent that their resilience is severely dampened. In this respect, participants highlighted how staff attitudes can have a do or die impact on patients and their families to retain such resilience.

The support of others throughout the treatment process is vital; for participants, the more isolated one is the more challenging the cancer journey is experienced. Employment and staff support were deemed essential by participants so much so that the wish was expressed for other patients going through cancer treatment to receive similar support. In the cancer journey support is needed even for the significant others who accompany patients on their frequent contact with health services; keeping the "working hat" on was described as "sanity and some normality" to most of the interviewed families living such an illness journey.

Patients' understanding of their illness situation, together with an understanding of patients' inner strengths is critical. Different nuances of the concept of health literacy were referred to by participants when they spoke of hospital professionals' skills used, throughout the cancer process, to build and enhance their (the patients') understanding versus simply being led.

The cancer treatment journey, irrespective of the type or age, is a high impact passage. Participants were anxiety ridden, felt vulnerable, frail, scared, agitated, angry and frustrated at their weak, 'uncooperative' body, disappointed, even shocked that family members had to cope with a lot, while accompanying them. Families require super reassurance, at home more and more, having to face new

situations alone. Findings brought out an interesting uniqueness of who the significant others accompanying patients can be. In this research the supportive persons were an elderly mother, a spouse, a sister, children; and the accompanying person readily emulated the patient's contextual story. Such context brings out the importance of recognising one's uniqueness and one's specific needs during the cancer journey.

Five key conclusions can be drawn from these findings.

5.2.1 Cancer patients recognise the good service aspects

Participants in this study clearly recognised the strengths of the health services that accompanied them in their cancer trajectory. Even though they battled with life and death issues, cancer patients did not convey any sense of unrealistic expectations. The more they understood the treatment process the greater their affinity to the services on which they depended. Clear signs of distress and insecurity arise when patients do not recognise the health services as making sense or when they lack the information to make sense of the services. This conclusion highlights the importance of health services provision that can be understood and followed by service users. The higher the complexity of the treatment process the more important it is for the health services provision to be rendered comprehensible for the service users, as is the case in cancer treatment.

5.2.2 Cancer patients need to trust health services

Considering that participants found themselves to be at the crossroads between struggling ahead and giving up, their disposition towards the treatment services

had to be built on the complete trust of the medical team. Without this trust, patients cannot subject themselves to the harsh realities of cancer treatment. This trust renders cancer patients and their families completely vulnerable in relation to the health services. Such vulnerability accentuates how critical the humanity of care is, especially at defining moments such as during periods of anticipation, when a cancer diagnoses is being communicated, when treatment regimes are being discussed, and in end-of-life deliberations. Health services personnel are key players in ensuring that patients' vulnerability and trust is revered.

5.2.3 Cancer patients need health services on which they can depend

One can interpret the cancer patients' general positive experience of the treatment service as a measure of the security these services impart on their users. Participants experienced the treatment services as services they could depend on and services they could count on when they required them. In this respect, a major lacuna in the treatment experience is when patients fall in between services, or when communication between services falls through, or when patients encounter services that are not cognisant and sensible to their specific needs. At critical moments, such as when cancer patients need to be hospitalised for whatever reason, patients encounter some of the worse experiences in their treatment journey, especially when admittance to MDH takes place through the general A&E. These are some of the most delicate moments for cancer patients, including situations of patients on advanced palliative care, at which time, the health services fail them.

5.2.4 Cancer patients need services that do not overburden them

The experiences of cancer patients clearly parallel the findings of other studies on the burden of the treatment process. While part of this burden is intrinsic to the nature of the treatment, participants recognise various instances that further overburden them and which need not necessarily be so. In this respect, the burden of being a cancer patient does not necessarily result from existing policies or protocols that, once identified, could possibly be addressed. A significant proportion of the burden services put on patients stems from the inability of services to adapt to the particular needs of each patient. It is clear that what works well for one person need not automatically work for another. Scheduling, treatment regimes, availability of psychosocial services, and other dimensions of the complex cancer treatment package can inflict less burden on patients when each patient's idiosyncratic needs are recognised. As Donabedian (1987) argued, patients' legitimate preferences "are the paramount consideration in defining the quality of the interpersonal process and of the amenities of care" (p. 81). The patient's particular needs include those of the patient's support structures, notably one's significant others and one's employment requirements.

5.2.5 Cancer patients need services that collaborate with their support structures

The multifaceted health services system within which cancer patients experience their treatment journey is made more complex by patients' various support structures. Patients live with families, friends, communities, work colleagues and other networks of intimate, informal and formal supports. Participants experienced the benefits of their support structures especially when these supports were in synch with the formal health services. The experiences of health

services that are sensitive to the needs of a patient's significant others or a patient's work commitments clearly highlight the importance of health services that take a systems' approach to their user's needs.

5.3 Recommendations

The five conclusions outlined above point towards some clear recommendations that can inform the planning, management and operations of public health systems for cancer patients.

5.3.1 Simplify provision of services, develop communication set-up, invest in health literacy

5.3.1.1 Recommendation 1.1

Simplify all aspects of cancer treatment services provision so that patients and their families are able to understand, make sense of, and follow the services and protocols they depend on.

5.3.3.2 Recommendation 1.2

Develop an information/communication link connecting the patient to professionals throughout treatment and post treatment as a practical process to assist anxiety reduction through the provision of accurate, clear and comprehensible information at the time that patients and their families need it.

5.3.1.3 Recommendation 1.3

Develop strategies to assess patient health literacy, and develop personalised strategies and services that address situations where patients' low level of health literacy compromises their ability to fully participate in the treatment journey.

5.3.2 Audit services for “humanity of care” quality, invest in “humanity of care” ongoing training

5.3.2.1 Recommendation 2.1

Regularly audit cancer treatment services provision for their “humanity of care” quality, involving representatives of service users or service users organisations in the process.

5.3.2.2 Recommendation 2.1

Develop continuous professional development provisions for all professionals working in the health system on managing challenging situations.

5.3.2.3 Recommendation 2.3

Develop strong systems of staff support in order to safeguard extremes in the continuum of care from “overwhelmed” to “matter of fact” professionals.

5.3.3 Develop services and clear protocols for lacunae that currently fail patients

5.3.3.1 Recommendation 3.1

Develop an admission policy and corresponding service at the OC to provide for cancer patients needing admission because of oncology-related medical complications, especially for palliative patients with frequent admissions.

5.3.3.2 Recommendation 3.2

Develop a palliative protocol that responds to the needs of cancer patients when referred to A&E, complemented by continuous professional development provisions for all professionals working in the health system on palliation systems of care so that all staff at the acute care hospital acquire the necessary

competencies in palliation systems of care. Palliation encompasses other disciplines apart from oncology, as per WHO definition; it is where a good life and a good death, with clear pain control protocols and family accompaniment are paramount over further investigations and futile diagnoses (Gawande, 2015).

5.3.4 Integrate a "burden of care" ongoing assessment in the cancer treatment protocol

5.3.4.1 Recommendation 4.1

Develop a "burden of care" assessment as an integral part of all cancer treatment services.

5.3.4.2 Recommendation 4.2

Use the "burden of care" assessment as part of continuous professional development provisions for all professionals working in the health system on the impact of cancer treatment on the lives of patients and their families and how to reduce the burden of treatment.

5.3.5 Embed in the treatment process patient's choice of formal and support networks

5.3.5.1 Recommendation 5.1

Expand the psychosocial systems within health to be readily accessible for the significant others and for the patient's identified support networks, ensuring a human link at different times of the treatment, with a wide range of complementary therapies, for instance autobiography and humour therapy, that recognise individual patient's needs and preferences.

5.3.5.2 Recommendation 5.2

Develop the necessary protocols and training to ensure that services of support are not offered prematurely (such as health workers, at diagnosis, offering information concerning end of life care) but are offered timely, and fast tracked services to ensure the provision of tangible support if and when needed.

5.3.5.3 Recommendation 5.3

Amend existing policies to ensure that all community services currently available for older persons become accessible to cancer patients when such services are indicated (for instance, Homehelp Service).

5.3.5.4 Recommendation 5.4

Support the development and the maintenance of 'self-help groups' and 'survivor mentors', especially for newly diagnosed patients.

5.4 Further Research

Two major limitations of this study can be addressed in future research focusing on the following questions:

- How do cancer patients who are children, young people, older persons, migrants, or disabled persons, their families and significant others live their experience as health service users during the illness?
- How do cancer patients evaluate the health care services they receive? How satisfied are they with the services? What areas for improvement do they identify? What patient expectations are not being met?

While the first set of questions can be studied through research adopting a similar methodology to this study, the second set of questions implies the use of ongoing quantitative strategies, incorporating a larger sample that allows for the generalisation of results to the wider patient population.

5.5 Concluding Thoughts

Cancer and its treatment trajectory continue to present challenges for the management of health systems, health workers and its service users. Cancer research supports the ongoing implementation of strategies best at addressing newer findings. Until such time as cancer is wiped out of the human experience, learning to live with cancer remains at the centre of the cancer treatment journey. It is a dynamic journey that changes continuously because the reality of the illness changes and the realities of those affected by the illness also changes. As Mukherjee (2011) argued "to keep pace with this malady you needed to keep inventing and reinventing, learning and unlearning strategies" (p. 470). Keeping in touch with patients' experiences and truly listening to their voices allows health systems to keep reinventing effective health strategies whereby structures and processes are continuously adjusted and monitored to fine-tune into patients' needs.

This study cannot be considered as a comprehensive evaluation of cancer treatment services in Malta. It was not intended to determine the value of such services. Nevertheless, by focusing on the lived experiences of six cancer patients some significant issues were identified that if addressed would add value to the public cancer treatment services in Malta and to the users of those services. Cancer patients know what is of value to them and also have a unique

insight on how to add value to what is of value to them. In this respect, a study on the lived experiences of six cancer patients shows itself to be a useful tool for the planning, management and delivery of public health services. Donabedian (1987) strongly argued that health service users "are also valuable, even indispensable, sources of information in judging the quality of care … and do, through expressing satisfaction or dissatisfaction, pass a judgment about many aspects of the process of care and its outcomes" (p. 81). Remarkably, most of the recommendations emanating from the experiences of the six cancer patients participating in this study do not require high expenditures to implement. Listening to, reflecting upon, interpreting and learning from the lived experiences of cancer patients can add value to health services at low cost. Moreover, in all decisions affecting patients, determining the effectiveness of health services outcomes depends on a thorough understanding of the individual patient's circumstances and preferences (Donabedian, 1988a). This study lends further support, albeit a small contribution, to Donabedian's strong contention on the necessity "to make a partner of the fully informed patient in deciding what 'greatest effectiveness' means" (p. 90) and for the health services to be driven by an "unwavering commitment to the welfare of each individual patient " (p. 99), what Donabedian refers to as "the cardinal virtue" (p. 99) to be embraced by all health services.

"It is the toughest thing I had to go through in all my life, it affects you physically and psychologically. It's a trauma for sure but thanks to God, my family and friends I have found the courage to continue fighting and believe I could make it ... You never really understand until you go through it but health professionals like social workers, chaplains etc. can be really of comfort to patients and relatives."

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Appendices

Appendix A: Participant Information Letter and Consent Form

A1. Participant information letter

Study: The Cancer Patient's Lived Experience of the Health System in Malta

Date

Greetings,

I am Christina Galea Curmi, a student at the University of Malta, currently reading for an MSc in Health Services Management. As part of my course, I am undertaking a research project in which I shall be studying the Health Systems as experienced by Oncology patients. This research is being supervised by Dr. Natasha Azzopardi Muscat, who is a Senior lecturer in the Department of Health Services Management, Faculty of Health Sciences, at the University of Malta.

I am writing this letter to kindly ask for your assistance in identifying adult participants, who have been diagnosed with cancer who have already had treatment and are recovering from said treatment.

Given the nature of my studies, I shall use a qualitative research strategy. Participants will receive an information sheet and will be asked to sign a consent form should they agree to participate. The participants will be briefed about the nature of this study. Their participation in the study will involve a 60 to 90 minute interview, depending on how much information the participants will want to share with me in the interview. The questions I shall be asking are related to the participant's experience as someone who came in touch with the local acute care health system.

Moreover, the participants will be informed that the interviews will be recorded only with their permission and such recordings will be erased once the end of the study is reached. Neither the recordings nor the transcripts of the recordings will have any notes that will identify the participants. Moreover, no one except me, my supervisor and the examiner will have access to the participant's replies. However not even the supervisor and examiner will have access to the participants identities.

Participation will be voluntary and thus participants will be free to decline from participating at any time during the study. They will also be free to decline from answering any questions. Should they want, I shall show them a copy of the transcript of their interviews and if at that time they want to delete any part of the transcript, they will be free to do so. This way, they will have complete control over which replies I use for my research study. The participant in the study has a right, under the General Data Protection Regulation (GDPR) and national legislation that implements and further specifies the relevant provisions of said regulations, to access, rectify, and where applicable, ask for the data concerning him or her to be erased.

Narrating their experience may bring back memories and emotions that might upset the participants. Should they want to seek professional support after the interview, I have made arrangements with the Psychology services at the Oncology Centre that are specialised in the field and available to help the participants.

Participants can contact me on [telephone number provided] to confirm their acceptance to take part in the study.

I would like to thank you in advance,

Regards,

Christina Galea Curmi, Researcher

Dr Natasha Azzopardi-Muscat, Tutor

A2. Consent for participation in interview research

Study: The Cancer Patient's Lived Experience of the Health System in Malta

Consent by Participant (and Family Member)

Date

I volunteer to participate in this research project by participating in an interview. I have read that the study is being undertaken by Ms Christina Galea Curmi as part fulfilment of her MSc in Health Services Management under the tutorship of Dr Natasha Azzopardi Muscat PhD, a Senior lecturer in the Department of Health Services Management, Faculty of Health Sciences, at the University of Malta. My participation in this research is voluntary. I understand that I will not be paid for my participation and that I may withdraw, without giving any reason and discontinue participation at any time.

I have read and understood the aims and method of the study as stated in the Participant's Information Letter and have asked any questions for clarification.

I understand that the researcher will not identify me by name in any reports obtained from this interview, and that my confidentiality as a participant in this study will remain secure.

I have read and understood the explanation provided to me and I voluntarily agree to participate in this study. The researcher can be contacted on tel: [telephone number provided] or via email on christina.galea-curmi.17@um.edu.mt. The tutor's email address is natasha.azzopardi-muscat@um.edu.mt.

I have been given a copy of this consent form.

Participant's signature [ ]

Christina Galea Curmi, Researcher, signature [ ]

Dr Natasha Azzopardi Muscat, Tutor, signature [ ]

Date [ ]

Appendix B: Participant Information Letter and Consent Form (Maltese version)

B1. Participant information letter (Maltese version)

Studju: Kif Pazjenti b'Kanċer jesperjenzaw is-Servizzi tas-Saħħa

Ittra ta' Informazzjoni dwar Parteċipazzjoni fir-Riċerka u Dikjarazzjoni ta' Kunsens

Data

Għażiż/a,

Jisimni Christina Galea Curmi. Jiena studenta fl-Universita` ta' Malta. Bħala parti minn dan il-kors fl-MSc, qiegħda naħdem fuq riċerka dwar l-esperjenzi tas-sistemi tas-saħħa minn pazjenti bil-kanċer. Is-superviżur ta' din ir-riċerka hija Dr. Natasha Azzopardi Muscat, lekċerer anzjana fid-dipartiment tal-Immaniġjar tas-servizzi tas-saħħa fi ħdan il-fakulta' ta' Xjenza Medika fl-Universita' ta' Malta.

Qiegħda nikteb din l-ittra sabiex ġentilment nitlob l-għajnuna tiegħek biex insib parteċipanti adulti li ġew mgħarfa li kellhom kanċer u li għalih diġa' ħadu trattament u qed jirkupraw mit-trattament.

Minħabba n-natura ta' dan l-istudju, għażilt li nuża riċerka kwalitativa. Il-parteċipanti ser jirċievu ittra ta' reklutaġġ u jiġu mitluba jiffirmaw formola ta' kunsens ġaladarba jagħżlu li jipparteċipaw. Il-parteċipanti ser jiġu mgħarrfa dwar x'jinvolvi dan l-istudju. Il-parteċipazzjoni tagħhom tkun tinvolvi intervista ta' madwar 60 sa 90 minuta, skond kemm il-parteċipanti jkollhom informazzjoni li jkunu jixtiequ jaqsmu miegħi matul l-intervista. Il-mistoqsijiet li ser nistaqsi huma relatati mal-esperjenza individwali tagħhom tas-servizzi tas-saħħa tul it-trattament tal-kanċer.

L-intervista tiġi rrekordjata biss bil-kunsens tagħhom u mħassra hekk kif it-tmiem ta' dan l-istudju jintlaħaq. La r-rekordjar u lanqas it-transkrizzjoni tar-rekordjar mhu ser jkollhom noti li jiddentifikaw l-identita' tal-parteċipanti. Barra minn dan, ħadd ħlief jiena, s-superviżur u l-eżaminatur tar-riċerka tiegħi mhu ser ikollhom aċċess għat-tweġibiet

tagħhom. Madankollu is-superviżur u l-eżaminatur tar-riċerka tiegħi xorta mhux ser ikollhom aċċess għall-identita` tagħhom.

Il-parteċipazzjoni tagħhom tkun volontarja u għalhekk għandhom id-dritt li jirrifjuta milli jieħdu sehem f'kwalunkwe stadju ta' dan l-istudju. Bħala parteċipanti għandhom ukoll id-dritt illi jirrifjuta li jirrispondi kwalunkwe mistoqsija. Jekk ikunu jridu, jiena inkun nista' nurihom kopja tat-transkrizzjoni tal-intervista tagħhom biex jekk ikun hemm xi parti mit-transkrizzjoni li huma jkunu jridu jħassru jkunu jistgħu jagħmlu dan bil-liberta' kollha. B'dan il-mod huma jkollhom il-kontrol sħieħ fuq it-tweġibiet li jien nuża għal dan l-istudju. Bil-liġi tal-"General Data Protection Regulation" (GDPR) u l-leġislazzjoni nazzjonali li timplimenta u tispeċifika l-aspetti relevanti ta' dawn ir-regolamenti, il-parteċipant għandu d-dritt li jaċċessa, jirranġa, u fejn japplika, isaqsi sabiex informazzjoni relatatata miegħu titneħħa.

Huwa possibli li r-rakkontar tal-esperjenza tagħhom iqanqal fil-parteċipanti ċertu memorji u emozzjonijiet li mhumiex pjaċevoli jew li jqanqlulek ċertu dwejjaq. Jekk ikunu jridu jfittxu għajnuna professjonali wara l-intervista, jiena għamilt arranġamenti mas-Servizzi psikoloġi fi ħdan iċ-ċentru tal-onkoloġija li huma speċjaliżżati f'dan il-qasam u li huma disponibbli biex jgħinu lil parteċipanti.

Il-parteċipanti jistgħu jikkuntatjawni fuq in-numru [numru tat-telefon provdut] jekk ikunu interessati jieħdu sehem f'dan l-istudju.

Nixtieq nirringrazzjak bil-quddiem.

Dejjem tiegħek,

Christina Galea Curmi, Riċerkatriċi

Dr Natasha Azzopardi Muscat, Tutur

B2. Consent for participation in interview research (Maltese version)

Studju: Kif Pazjenti b'Kanċer jesperjenzaw is-Servizzi tas-Saħħa

Kunsens tal-Parteċipant (u tal-Membru tal-Familja)

Data

Jien naċċetta li nipparteċipa f'dan il-proġett ta' riċerka billi nieħu sehem f'intervista. Nagħraf illi l-istudju qed isir minn Christina Galea Curmi bħala parti mill-istudji taghha fl-MSc fl-imaniġġjar tas-servizzi tas-saħħa fl-Universita ta' Malta, 2017-2019 taħt is-sorveljanza ta' Dr Natasha Azzopardi Muscat PhD, lecterer anzjana fid-Dipartiment tal-Immaniġjar tas-servizzi tas-Saħħa, Fakulta' ta' Xjenza fl-Universita' ta' Malta.

Il-parteċipazzjoni tiegħi f'din ir-riċerka hija volontarja. Nifhem li mhux ser nitħallas għall-parteċipazzjoni tiegħi u li nista nwaqqaf il-parteċipazzjoni tiegħi fi kwalunkwe ħin mingħajr ma għandi għalfejn nagħti raġuni.

Jiena qrajt u fhimt l-għan u l-metodu tal-istudju kif spjegat fl-ittra ta' informazzjoni u saqsejt il-mistoqsijiet li xtaqt għal klarifikazzjoni.

Jiena nifhem li r-riċerkatriċi ser iżżomm l-identita' tiegħi mistura fi kwalunkwe rapport li tikteb ibbażat mill-intervisti, u li l-kunfidenzjalita' tiegħi ser tkun salvagwardata.

Jiena qrajt u fhimt l-ispjegazzjon li ngħatajt u volontarjament naċċetta li nippartecipa f'din ir-riċerka. Ir-riċerkaturiċi tista' jiġi kkuntatjata fuq in-numru [numru tat-telefon provdut] jew b'emajl fuq christina.galea-curmi.17@um.edu.mt. L-indirizz tat-tutor hu natasha.azzopardi-muscat@um.edu.mt

Jien ingħatajt kopja tal-formola ta' aċċettazzjoni tal-parteċipazzjoni tiegħi fir-riċerka.

Firma tal-parteċipant [ ]

Christina Galea Curmi, Riċerkatriċi, iffirmata [ ]

Dr Natasha Azzopardi Muscat, Tutur, iffirmata [ ]

Data [ ]

Appendix C: Interview Schedule for the Semi Structured Interviews (English version)

Research Question

How do cancer patients, their families and significant others live their experience as health service users throughout the illness?

Interview Schedule – (Schedule will be adapted accordingly to each particular interview, and therefore not all questions will be asked in each case).

1. Can you tell me what place the health services have in your life at the moment?
 Possible prompts: Do you have frequent appointments? How do you feel about your current contact with the health services?

2. Can you tell me about a recent time when you used the health services?
 Possible prompts: When did you have your last appointment? How did it go? What happened? How was it? How did you feel?

3. How long have you been in touch with the oncology health services?
 Possible prompts: Before SAMOC?

4. Can you tell me how you got to know about your illness?
 Possible prompts: How did it happen? How did you cope? How did it feel?

5. Can you describe your first encounters with the health services because of your cancer?
 Possible prompts: What did it involve? What happened? Whom did you first contact? Who from your family accompanied you?

6. How would you describe this beginning of your treatment journey?
 Possible prompts: How did it feel? Did anything help? Did anything make it worse?

7. What did the cancer diagnosis mean for you at that time? And now?
 Possible prompts: Family, work, friends, work colleagues, way of life, financially?

8. And how do you describe the way the new treatment regime affected your life?
 Possible prompts: Was it flexible? Overbearing? Intrusive? Supportive?

9. What did it involve and how did you manage to keep up with the treatment regime?
 Possible prompts: Keeping up with doctor appointments? Medical tests? Hospital appointments? Combined treatment bookings?

10. Can you describe the way your family or friends or other close persons experienced the health services through your treatment journey?
 Possible prompts: Were they involved? Did they feel part of the treatment regime? Were they allowed to support you?

11. What are the main differences between a good day at the health services and a bad day at the health services?
 Possible prompts: Can you describe a particularly bad experience? What happened? How did you feel? And a particularly good experience? What happened? How did you feel?

12. How do you feel every time you need to be in touch with the health services again?
 Possible prompts: Are you informed about the nature of an appointment when you are called in for one?

13. How do you think your life would be different if you had to experience treatment services in a more advanced country?
 Possible prompts: Do you think you would get more information? More services?

Appendix D: Interview Schedule for the Semi Structured Interviews (Maltese version)

Il-Mistoqsija tar-riċerka:

Kif il-pazjenti tal-kanċer, il-familji tagħhom, u nies sinjifikanti f'ħajjithom jgħixu l-esperjenza bħala klijenti tas-servizzi tas-saħħa waqt il-marda?

Skeda għal intervista mal-Parteċipanti (L-iskeda tigi għaddattatha skond l-intervista, għalhekk mhux bil-fors jiġi mistoqsi kollox).

1. Tista' tgħidli x'rwol għandhom is-servizzi tas-saħħa f'ħajjtek fil-preżent?
• *Mistoqsija supplimentari*: Ikollok appuntamenti ta' spiss? Kif tħossok dwar il-kuntatt preżenti tiegħek mas-servizzi tas-saħħa?

2. Tista tirrakkontali dwar appuntament riċenti li kellek mas-servizzi tas-saħħa?
• *Mistoqsija supplimentari*: Meta kellek l-aktar appuntament riċenti? Kif kien? X'ġara? Kif ħassejtek?

3. Kemm ilek f'kuntatt mas-servizzi taċ-Ċentru tal-Onkoloġija?
• *Mistoqsija supplimentari*: Qabel SAMOC?

4. Tista tgħidli kif sirt taf dwar il-marda tiegħek?
• *Mistoqsija supplimentari*: Kif ġrat? Kif kampajt? Kif ħassejtek?

5. Kif tiddeskrivi l-ewwel kuntatti tiegħek mas-servizzi tas-saħħa minn meta sirt taf
dwar il-kanċer?
• *Mistoqsija supplimentari*: X'kienet tinvolvi? X'ġara? Lil min infurmajt l-ewwel? Min mill-familja tiegħek ġie miegħek għand il-professur?

6. Kif tiddeskrivi l-bidu tat-trattament tiegħek?
• *Mistoqsija supplimentari*: Kif ħassejtek? Għinek xi ħaġa? Kien hemm xi affarijiet li għamlulek l-esperjenza għar?

7. X'fissret għalik dak il-ħin l-aħbar li kellek kanċer? U issa?
• *Mistoqsija supplimentari:* il-familja, ix-xogħol, il-ħbieb, il-kollegi tax-xogħol, l-istil ta' ħajja, il-finanzi?

8. U kif tiddeskrivi l-mod li t-trattament affetwalek ħajjtek?
• *Mistoqsija supplimentari*: Kienet sistema flessibli? Ta' piz enormi? Daħħlu f'ħafna dettal personali? Kienu ta' sapport?

9. X'involviet u kif irnexxilek timmaniġja l-proċess tat-trattament?

Mistoqsija supplimentari: Biex iżżomm mal-appuntamenti tat-tobba? Testijiet mediċi? Appuntamenti tal-isptar? Appuntamenti tat-trattamenti differenti?

10. Kif tiddeskrivi it-tibdil fl-esperjenza tiegħek tas-servizzi tas-saħħa minn mindu bdejt it-trattament għall-issa?
• *Mistoqsija supplimentari*: L-affarijiet huma aħjar? Għar? Tarahom differenti?

11. Tista tiddeskrivi kif il-familja tiegħek, jew il-ħbieb jew il-persuni l-aktar għal qalbek esperjenzaw is-servizzi tas-saħħa tul it-trattament?
• *Mistoqsija supplimentari*: Kienu involuti? Ħassewhom parti mittrattament tiegħek? Setgħu jagħtuk sapport?

12. Liema huma d-differenzi ċari bejn ġurnata tajba u ġurnata iebsa fil-kuntatt tiegħek mas-servizzi tas-saħħa?
• *Mistoqsija supplimentari*: Tista tiddeskrivi esperjenza partikolarment iebsa? X'ġara? Kif ħassejtek? U esperjenza partikolarment tajba? X'ġara? Kif kienet?

13. Taħseb li ħajtek tkun differenti li kieku kellek tesperjenza servizzi ta' kura f'pajjiz
aktar avvanzat?
• *Mistoqsija supplimentari*: Taħseb li tingħata aktar informazzjoni? Tingħata aktar servizzi?

Appendix E: Types of Questions Used to Develop Interview Schedule

(Descriptive) Can you tell me something about you?

(Narrative) When did you hear the word Cancer for the first time? / How did you get to know you had cancer?

(Structural) When did you get in touch with the Health services? What did it involve?

(Narrative) How would you describe your experience of the Health system after you were diagnosed with cancer?

(Structural) What treatment regime did you have to follow?

What did it involve to keep to Doctors appointments, hospitals appointments, combined treatment bookings, if any, etc?

(Narrative) What do cancer services mean to you?

(Contrast) What are the main differences between your first contact with the health setting and now?

(Evaluative) How do you feel now that the intensive treatment is over? Can you tell me more?

(Circular) How do you think your family sees you now? Why?

(Comparative) How do you see yourself now when compared to the first hospital contact? How do you think your family/significant others see the health system now when compared to their first hospital contact? In what way?

Appendix F: Participants' Quotations in Maltese and English

F1. Positive Treatment Experience (section 4.3)

Q1 Alex: *"Jiena kelma waħda għandi għas-servizz – eċċellenti."*

"I only have one word to describe the service – excellent."

Q2 Henry: *"Hawnhekk peress li ma jkunx hawn il-massa tan-nies li jkun hemm Mater Dei, hawnhekk iktar tħossok kalm, fis-sens għax hemm min jgħinek."*

"Here because there is less influx of people like there is at MDH, here you feel calmer, in the sense that there is staff to assist you."

Q3 Alex: *"Għalija jiena kont fl-aħjar sptar li qatt inzertajt u nispjegalek għala – bħala servizz kien impekkabli u niskorjah bħala eċċellenti, bħala kura nemmen li ppruvaw ituni l-aħjar kura li hawn teżisti fid-dinja."*

"For me I was in the best hospital that I have ever come across and I shall explain why – as a service it was impeccable and I give it the highest score, in terms of treatment I believe they tried to give me the best treatment that presently exists in the world."

Q4 Henry: *"Aħna se naħdmu bħala team igifieri mhux jien se nitilqek issa, imma l-main consultant tiegħek issa se jkun dan."*

"We shall be working as a team, meaning I will not be abandoning you. Your main consultant will be him."

Q5. Henry: *"Le aħna qegħdin advanced hawn."*

"We are very advanced here." (referring to MDH and the OC)

Q6 Pat: *"Kif ikellmuk qishom xi ħadd li ilu jagħfek, you are not a number quddiemhom, they're very caring, very caring."*

"The way they talk to you makes you feel like you've known them all along, you are not a number, they're very caring, very caring."

Q7 Beth: *"Dik qisha l-mummy tiegħi jien, qed tieħu ħsiebi."*

"She is like my mummy, taking care of me."

Q8 Henry: *“Tintelaq iġifieri fil-mistoqsijiet li tagħmillu u li jagħmillek hu … mhux dik il-biża li dħalt quddiem konsulent u tgerrixt.”*

“You let go in the questions you put to him and he puts to you … not the fear that you are in front of a consultant and feel overwhelmed.”

Q9 Thomas: *“Jekk is-sistema ma tħallikx tagħmel ċerta affarijiet ser tkissrek.”*

“If the system does not allow you to do certain things it will break you.”

Q10 Beth: *“Jiena nhossni xxurtjatha li għandi dan is-servizz li jagħmlulek ħajtek faċli aktar.”*

“I feel lucky to have such services that make my life so much easier.”

Q11 Jill: *“Aħjar mhux il-bogħod mill-familja, bqajt hawn Malta stess hu? Ħafna, ħafna apprezzajt bqajt Malta stess.”*

“Better not away from my family, I remained here in Malta eh?; I really appreciated a lot that I remained in Malta.”

Q12 Pat: *”Imma qatt ma noqgħod ngħid għax ser indum.”*

“I never comment on how long we have to wait.”

Q13 Beth: *“Ma kontx nagħti kas jien. Ngħid għandna ġurnata hemm hu.”*

“I didn’t use to bother. I say to myself that we have a day there.”

Q14 Henry: *“L-istennija “mhux ħafna. Mhux ħafna, xhur ta’ jigifieri. Forsi, kemm xahrejn? Ma kienx hemm xi tul ta’ żmien.”*

“The wait wasn’t long. Maybe two months? There wasn’t a long period of time.”

Q15 Pat: *“Ifhem kieku sew kieku jkollok test tad-demm u kollox f’nofs ta’ nhar”.*

“It would be very good if one would have the blood test and the other tests in same morning.”

Q16 Pat: *“Anke, per eżempju l-ġimgħa l-oħra kelli l-appuntament it-Tlieta, kien l-onkoloġija u l-Erbgħa kelli għand is-surgeon. Ukoll kelli d-dwejjaq ghax kelli mmur darbtejn wara xulxin l-isptar.”*

“For example, even last week I had an appointment on Tuesday, it was at oncology and Wednesday I had an appointment with the surgeon at MDH. I was anxious at having to go twice in a row to hospital.”

Q17 Beth: *“Jiena ngħidilhom l-iktar kmieni għax minħabba d-daddy u ħalli mbagħad mhux inżommu jekk irid jagħmel xi ħaġa.”*

“I tell them the earliest (appointments) because of my daddy so that like that I do not keep him from taking care of other things, if he needs to.”

Q18 Jill: *“Iva aħjar hekk, jiena għaliha kieku aħjar, mhux trid issib min ser iwasslek. Min ikun jaħdem miskin ma jistax joqgħod ġej u sejjer mix-xogħol”.*

“Yes better that way, for me much better not needing to find someone to get you to hospital. Those who work cannot stay coming and going from work to take someone for a hospital appointment.”

Q19 Thomas: *“L-appuntamenti faqqgħuwli l-mobile għax jiena għandi l-app u tircievi l-messaġġi u ‘l ħin kollu nirċievi l-messaġġi. Iġifieri jkolli appuntament, ġieli jdoqqli 4 darbiet”.*

“They blasted my mobile with appointment messages as I have the app and I receive messages and I receive messages all the time. So, I’ll have an appointment, sometimes I receive 4 messages for the same appointment.”

Q20 Beth: *“Dak kelli nixtrieh jien (Avastin) .. U kiltha hekk! Il-mummy meta qaltilna (l-konsulent), qaltilha illaħwa, 30 sena ilu ma kellniex lil Puttinu u issa ħa jkollna nixtruha!”*

“I had to buy it (referring to Avastin). I had to lump it! When (oncologist) told my mother, mum said ‘Oh my 30 years ago there was no Puttinu to support us (in the UK), and now we will have to buy it!”

F2. Overcoming identified service limitations (section 4.4)

Q21 Maggie: *“Meta semma l-kelma ‘urġenti’ jiena magħha qbadt, u allura ffrikjajt u qgħidt dan huwa każ li ma jistax jistenna.”*

“When he used the word ‘urgent’ it stuck with me that it’s a case that can’t wait and freaked out.”

Q22 Thomas: *“Jiena kieku qaluli ‘isma, ara issa hemm proċess ta’ 4 weeks li jrid isir u inti ma tistgħux tagħmluh qabel 4 weeks …jekk inti jkollok ftit moħħ tgħid ‘isma dan hemm proċess li trid tgħaddi minnu s-sistema ... Issa jien ma nistax mmur ngħidlu ‘aqbad għamilhom fl-aħħar tax-xahar ħa neħles ħalli nara x’hemm u x’m’hemmx.”*

“Had I been told that there is a process of 4 weeks which need to happen and you cannot do it before the 4 weeks .. if you can reason with the information given you say so there is a process that the system needs to go through ... and I cannot tell him to do it at the end of the month so I get it over and done with so I get to know what there is and there isn’t.”

Q23 Maggie: *“Kont inkun hawnhekk nistenna u … tibda tgħid ‘kif spiċċajt hawn?’ u tibda tibki u inti tibda tħossok qegħda ġo post waħdek u f’dak iż-żmien fejn ikollok bżonn l-għajnuna”.*

“You would be here waiting ... and you ask ‘How did I end up here? And you start crying and you start feeling that you are all alone and it is in those moments where you need the help.”

Q24 Beth: *“L-emerġenza vera jiġifieri jagħtuk servizz, u jibdewlek minn fuq s’isfel testijiet li kien hemm fil-bidu. Issa l-aħħar darba li mort, aħjar, ma kellhomx aċċess għal file tiegħi mill-Emerġenza. Għallura riedu joqgħodu jsaqsu lili x’ħadt u x’ma ħadtx, l-istorja mill-bidu”.*

“At Emergency it is true they give you the full service and they do tests for every part of your body just like in the beginning. Now the last time I went it was even better as they did not have access to my file from the Emergency (sarcastic) so they had to stay asking me (the patient) what I took and what I had not taken, my history from the start.”

Q25. Beth: *“L-Emerġenza ma jafux, u anke fejn jitfgħuni. Imma mbagħad ngħidilhom speċi kkuntatjaw lill-Onkoloġista u bdew jagħmlu hekk.”*

“At A&E they do not know, nor where I should be admitted. But then I started telling them to link with my oncologist and they adopted that process.”

Q26. Beth: *“Kull ward mort jien … kieku ċ-ċentru tal-onkoloġija kien ikbar .. għall-emerġenza tagħna m’ghandniex għalfejn immorru Mater Dei.”*

“I have been in every ward [at MDH] … with a larger OC … we would not need to go to MDH for our needs.”

F3. Humanity of Care (section 4.5)

Q27 Patrick: *"Jien kif tlajna mill-isptar bqajna sejrin għand it-tabib, din ġewwa u jien barra, nċempel lil ħuti fit-triq … xokk kbir, xokk kbir, tibda ħafna ħsebijiet ġo moħħhok, lanqas naf x'inhu għaddej. Imma hi mbierek'Alla kienet."*

"When we left the hospital we went straight to the doctor, my wife went in and I stayed outside calling my siblings. I had a big shock, big shock, you start thinking lots of things, not knowing what is going on, unlike her (the wife)."

Q28 Beth: *"Jiena sa dak il-ħin kont waħdi jiġifieri l-bomba tagħieli waħdi. Insomma mbagħad ġejt l-Emerġenza u tefgħuni gynae."*

"At that moment I was all alone which means that the bomb exploded while I was all alone. Anyway, then I came to emergency and I found myself at gynae."

Q29 Maggie: *"Is-servizz li tawna kien tajjeb ħafna, l-unika ħaġa ma nafx kif inhi imma naħseb kif jgħidulek the news the first time kienet ftit xokkanti, hi xokkanti kemm trid."*

"We had a very good service however the way news is given the first-time round was shocking, very shocking indeed."

Q30 Maggie: *"L-Ispeċjalisti just kemm jgħidulek li r-raġel ħadnielu l-biopsy u minnha rriżulta li għandu cancer. Inti dak il-ħin la reaction ma jkollok, la taf kif ser tirrispondi, tgħid imma qed jgħiduli xi ħaġa li hija vera jew le?"*

"The specialists just tell you that we carried out a biopsy which resulted cancerous. At that point you have no reaction, you do not know how to respond, and you begin to ask whether what they are saying to you is true or not?"

Q31 Beth: *"Għandek il-vina qegħda tajba, qegħda mdaħħla tajba. U int issa tkellimt? Għada kemm titlaq it-tabiba tan-night? ... Ma ridditx tneħħijieli."*

"The vein is good, the canula is inserted well. How come you only spoke now? The night doctor has just left ... and she did not want to remove it for me."

Q32 Alex: *"Tagħtni ġewwa ħafna, u anke għal mara, u ħadtha bi kbira aktar għax il-mara qabdet tibki meta kien qed jgħidilna u speċi ta', aktar u aktar."*

"It affected me a lot, and even my wife, and I got worked up about it even more as the incident brought my wife in tears, so more and more."

Q33 Pat: *"Hemm ners partikolari, jigifieri kienet iċċempilli, ħelwa wisq, u wara l-operazzjoni ġiet ma ġenbi u qagħdet tkellimni. Sibt ħafna, ħafna għajnuna."*

"There is a nurse who used to call me, very sweet, and after the operation she came near me and stayed talking to me. I found a lot, and a lot of support."

Q34 Alex: *"Eżatt għax fl-aħħar mill-aħħar taf kemm taf, quddiemek għandek bniedem fraġli għax jekk tarani dak iż-żmien u tarani llum tgħid bniedem kompletament differenti, taf kemm il-darba kont nibki l-isptar!"*

"Exactly as no matter how much you know, in front of you there is a fragile human being because had you seen me during the treatment phase and you see me now you say I am a completely different person, you know how often I cried in hospital!"

Q35 Maggie: *"Huma vera jagħtu t-treatment u hekk imma ma tkunx għaddejja fuqek. Il-konsulent joħroġ minn hemm, jinsiek u jiltaqa' ma xi ħadd ieħor pero' għalik dik il-kelma tiegħu tkun għalik ta' importanza kbira."*

"It is true that they (doctors) give treatment etc but they are not the ones going through the illness just like you are. The consultant leaves the clinic, forgets you and meets someone else, but for you that word of his is critical."

Q36. Pat: *"Bhala kuntatt ma' l-isptar ifhem tajjeb meta bħal ma qegħdin ngħidu meta ssib it-tabib li qed ikellmek u jispjegalek u jieħdok bil-kalma … u ħażin … meta forsi ssib dak il-wieħed qisu "ejja ħa neħilsu". Jiena inkun irrid illi jkellimni naqra bil-ħlewwa għax jiena naqra sensittiva."*

"As a link with hospital it is good when you have a doctor who is talking to you (the patient) and he is explaining in a calm manner .. and it is bad … when you find someone who is considering you just another patient. I want them to talk to me gently as I am a bit sensitive."

F4. Centrality of support (section 4.6)

Q37 Pat: *"Jiena qatt ma kelli dubju li tal-familja jħobbuni, jiġifieri r-raġel, it-tifel, ħuti, ħu r-raġel, imma minn din l-esperjenza hemm rajt kemmm għandhom imħabba għalija, ħassejtha, hekk qgħidt very jħobbuni .. u jiġu kuljum, kuljum, u jsaqsu."*

"I never doubted that my family love me, I mean my husband, my son, my siblings, my brother in law, but from this experience I saw the amount of love they have for me, I felt it and I said 'they really love me' .. and they come every day, and they call."

Q38 Jill: *“Kelli l-familja. Kelli r-raġel, kelli t-tfal li nirrispetta”.*

“My family, I had my husband and I had my children who I really respect.”

Q39 Beth: *“Il-mummy hekk ... tiġi hawn, iġġibli l-ikel … Hi mhix ser tintelaq u toqgħod tibki f’rokna.”*

“My mother is like that ... she comes to hospital and brings me food .. she will not put herself in a corner and stay crying.”

Q40 Thomas: *“Aħna dejjem żammejna l-bogħod. Imbagħad din il-marda bidlet kollox għax dawn spiċċaw isajruli, jieħdu t-tfal l-iskola kuljum, kemm il-darba wara l-iskola żammewhom għandhom, ġieli raqduhom għandhom, affarijiet li ma konnhiex nagħmlu qabel għax dejjem konna ngħidu dawn tagħna u nrabbuhom aħna.”*

“We always kept back (refering to their parents’ request to have the children at them). Then this illness changed everything as my parents ended up cooking for me, taking the children to school daily, at times after school they kept the children at them, with sleepovers too, things that we did not use to do before as we used to say ‘they are our children and we bring them up.”

Q41 Thomas: *“Jiena x-xogħol qaluli għamel li trid, fis-sens, ara x’għandek bżonn u allura that is already a plus.”*

“I was told from work to do what I wanted, meaning see what you need and thus that is already a plus.”

Q42 Thomas: *“So inti għandek sapport miż-żewġ xogħlijiet, għandek sapport mill-ġenituri, kelli oħt il-mara kważi kienet issajjar kuljum … sakemm ikollok is-sapport fid-dinja, mhux ser tibqa’ daqshekk normali l-ħajja, imma ma tiġiex f’daqshekk periklu.”*

“So you have support from the two places of work, you have support from the parents, I had support from the sister in law cooking .. as long as you have support in this world, life will not remain so normal, however you will not find yourself in so much danger.”

Q43 Beth: *“Tgħid istra kif hu reġa ħareġ hu? Imma mbagħad nkun lesta li niġġielidha jien.”*

“You say how could it be that I got it again? But then I gear up to fight it.”

Q44 Henry: *“Tidħol dik ix-xi ħaġa go fik li inti, kif taqbad tgħid, parti mis-soċjeta’. Għalkemm għandek il-problemi tiegħek inti xorta bqajt parti mis-soċjeta’. Mhux mela jiena għax għandi din il-problema mela jiena 1/6 tas-soċjeta’. Le. Nibqa parti mis-soċjeta’, li nista nagħmel ġid sa fejn nista’ nasal, nagħmlu xorta.”*

“There is something in you that keeps you believing that you are part of society. Although you have problems you still form part of society; not because of this problem I form only one sixth of society, no. I remain part of society where I can still do good up to where I can get to, but I can still do it.”

Q45 Thomas: *“Inti titlaq mill-punt li tgħid ‘isma speċi ta’, jien irrid nibqa’ ngħix, u ngħix ħajja normali’. Għalhekk qgħidtek ‘jiena qatt ma ħassejtni pazjent għax jiena kont immur hemmhekk qisni qed immur any other appointment.”*

“I started my contact with the OC with the premise that I want to keep living, and I want to live a normal life. I never felt like a patient as I used to go there (for hospital interventions) like I was attending any other appointment.”

F5. Burden of Treatment (section 4.7)

Q46 Alex: *“L-ewwel ħaġa meta bniedem ikun f’kundizzjoni hekk billi tgħidlu ħafna affarijiet jew tgħidlu ħafna hekk jew ittih ħafna karti għalxejn. Trid tkun straight to the point ... u tgħidlu eżatt, mela inti ser tidħol hekk, ser ikollok hekk u hekk, bullet points.”*

“First and foremost, when the individual is going through something like this (a recent diagnosis) telling him a lot of information, or you tell him so or you give him a lot of papers is futile. You need to go straight to the point .. and tell him the exact information, when he is to come in, what he will be taking, experiencing etc in bullet form.”

Q47 Alex: *“L-aktar oġġett li kien itini jiena ... hija li kont inħossni drejnjat, li kien hemm żmienijiet li lanqas tazza mimlija te’ ma kont niflaħ … meta kont naf li jiena bniedem indipendenti, b’saħħti … imma f’daqqa waħda għal kull oġġett irrid l-għajnuna jibda jilgħablek moħħok.”*

“The worst issue I had that really frustrated me ... was that I felt so drained, so much that there were times when I couldn’t even hold a cup of tea in my hands ... especially when you consider that I was an independent healthy person ... and then all of a sudden for everything I need assistance, your reasoning starts playing games.”

Q48 Henry: *“Jiena meta t-tabib jgħidli inti għandek hekk, għandek hekk, għandek hekk, se tħoss hekk u se tħoss hekk ... mbagħad ngħid wara, jien t-tabib tiegħi, jien se nħoss tiegħi. Jien ma nistax inħoss tiegħek, l-uġiegħ minn fejn ġej u hekk, jiġifieri all right, it-tabib ser jgħallmek, se jtik triq minn fejn se tgħaddi, ħa ngħidu hekk. Fl-istess ħin it-triq tagħmilha inti ukoll.”*

“When the doctor tells me ‘you have this, you have this and that, you shall feel this and this ... afterwards I tell myself, ‘I am my own doctor, I feel my own pains. I cannot feel yours, your source of pain. So all right the doctor is there, he will explain to you, he will show you the path of treatment that you are expected to pass from, so to speak. At the same time the road can be steered by yourself too.”

Q49 Alex: *“Kull appuntament illum il-ġurnata sar għaliha ta’ twerwir. Ta’ twerwir għala? Għax daqs kemm ma kontx nibża mill-isptar illum sirt nitwerwer minnu, anke ngħaddi minn ħdejh.”*

“Every appointment for me has become a frightening experience. Why is it frightening? Because as much as I did not use to fear the hospital, I have become terrified of it, even just passing near it.”

Q50 Pat: *“Il-ġurnata ta’ qabel, dejjem, ikun ta’ x’hiex ikun l-appuntament, dejjem inkun daqxejn anzjuza jigifieri, dejjem anke jekk naf li mhux ser ikunu affarijiet kbar, dejjem ikolli daqxejn ta’ eċċitament.”*

“The day prior to every appointment, irrespective of what the appointment is, I am always somewhat anxious, always, even if I know that there will not be major concerns, an appointment is always accompanied by a certain amount of fear.”

Q51 Alex: *“Il-kelma kanċer u chemo huma, dawn mhux ser tmur tnaddaf snienek. Ser jidħol ħafna valeni, ħa nsejħilhom hekk, suppost dawn il-valeni ser jagħmlulek it-tajjeb pero’ ma għandek l-ebda garanzija għax, inti daqsi taf, x’lista ta’ side effects. Voldieri dawn joqtlulek ħaġa u joqtlulek ħaġa oħra.”*

“The words ‘cancer and chemotherapy’ are not something like the cleaning of teeth. A lot of toxins will enter your body, so to speak, and these toxins are meant to do you good, however there is no guarantee, as you know as much as I do, that there is a list of side effects felt. Meaning these kill some things in the body and they kill other things too.”

Q52 Beth: *“Issa jiena I’m a fighter, imma xorta jiġu mumenti … li tibda tirrejalizza ċertu affarijiet.”*

“I am a fighter, however, doubtful moments come where one starts realising certain things.”

Q53 Beth: *"Ir-raġel miskin qed jieħu ħafna paċenzja. Heqq l-affarijiet li kont nagħmel jien irid jagħmilhom hu ... ifhimni r-raġel ma tantx juri imma jinkwieta. U ġieli beka wkoll ma ħutu u hekk."*

"My husband is having to be very patient. All the things I used to do now have to be done by him ... my husband does not show it but he worries. And at times he cried also with his siblings etc."

Q54 Alex: *"Il-ġurnata tal-llum qisu xi ħadd jiftaħlek għajnejk u literally you are seeing a clear picture."*

"These days it's as if someone opened your eyes and literally made you see a clearer picture."

Q55 Maggie: *"Ma tistax tħossok tajjeb għax inti tħossok helpless."*

"You cannot feel good as you feel helpless."

Q56 Beth: *"U qabel meta kont niekol sew, jiena u l-mummy qisna picnic. Inġibu s-sandwiches, il-ħin kollu nieklu u nieħu l-chemo ... jiġifieri aħna nieħduha hekk, anke l-mummy."*

"Before when I was eating well, me and my mother (used to prepare) like a picnic. We get sandwiches, all the time eating and taking chemo at the same time ... we take things like this, even my mother."

Q57. Henry: *"Jekk il-moħħ tibqa' twaħħallu, ittih, ittih, ittih, ittih ġo fih fl-aħħar ser jgħidlek stop issa ta.'"*

"If you keep hitting your head there will come a point where it will tell you STOP."

Q58 Thomas: *"Għidli x'hemm bżonn u nimxi magħha."*

"Tell me what needs to be done and I will follow (referring to the radiographer)"

Q59 Maggie: *"Pero vera meta tiġi fuqek, sewwa qed tgħid, tkun strong aktar milli taħseb, vera."*

"It is true when you get to face it, you are right, you are stronger than you think."

Q60 Jill: *"Qgħidt m'hemmx x'tagħmel irrid inkompli bil-ħajja."*

"I have no choice except go on with life."

Appendix G: Taxonomy of Burden of Treatment

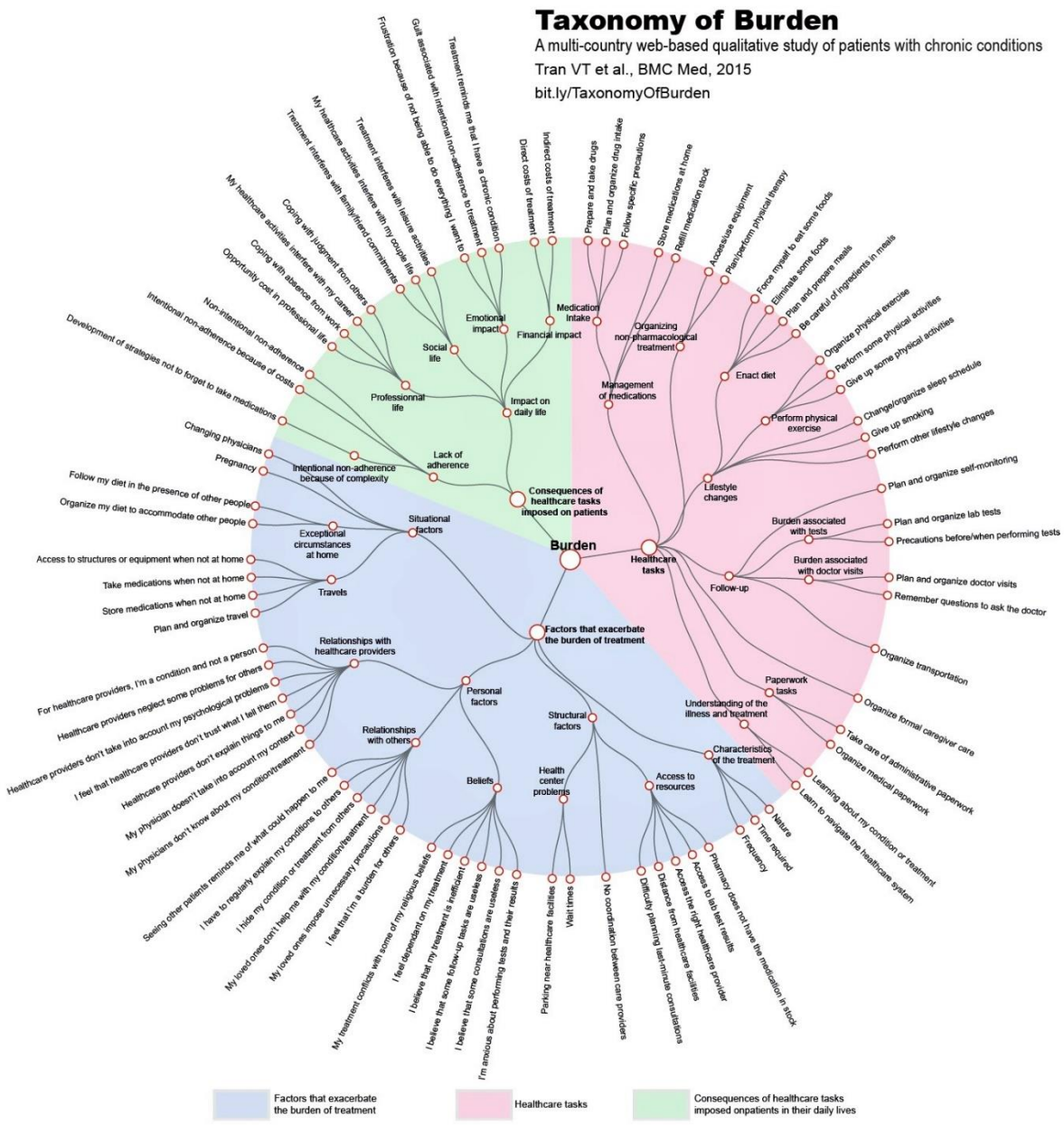

Figure 2: Taxonomy of the Burden of Treatment (Tran, Barnes, Montori, Falissard & Ravaud, 2015, p. 120)

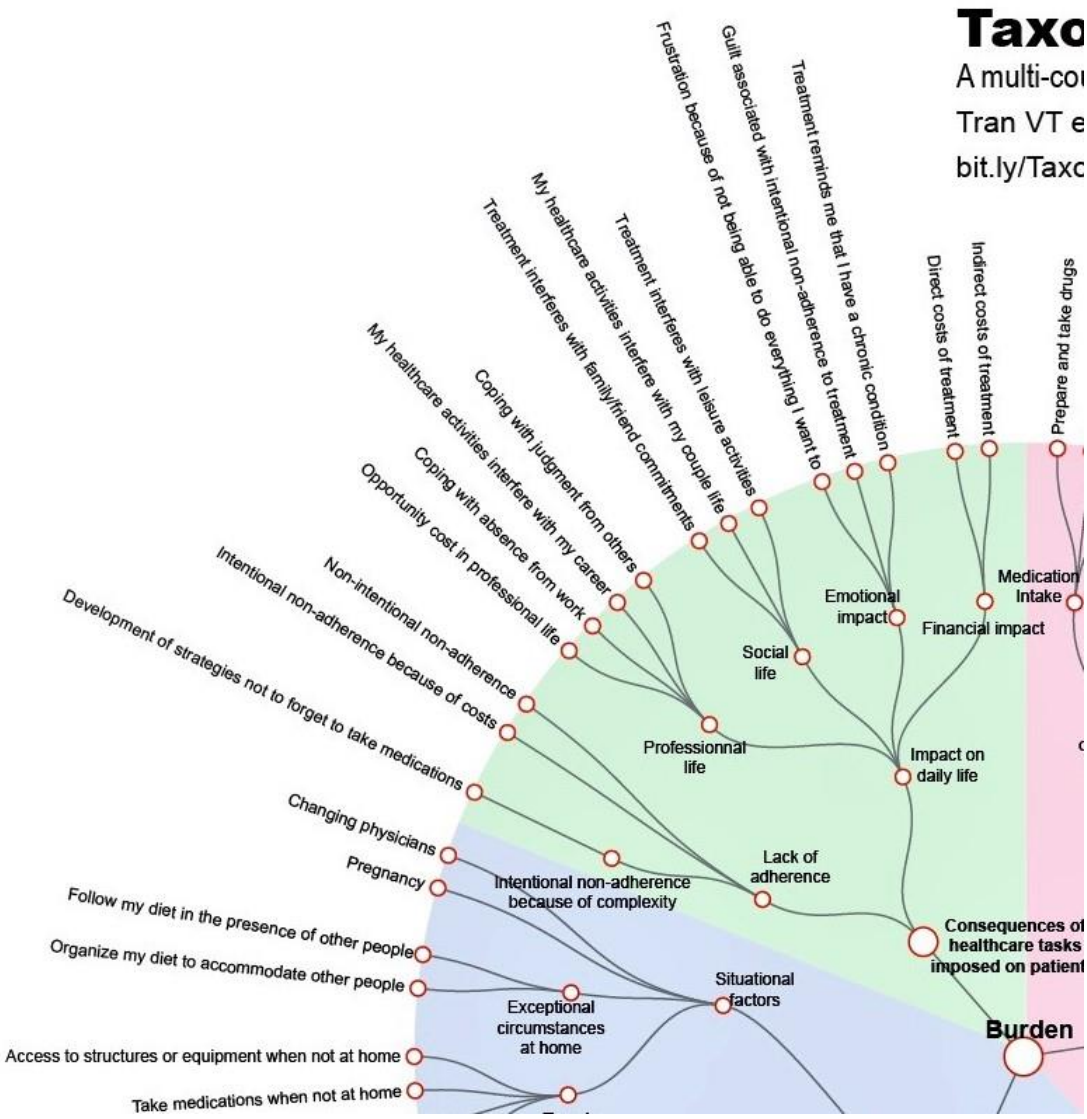

Figure 3: Detail from Taxonomy of the Burden of Treatment (Tran, Barnes, Montori, Falissard & Ravaud, 2015, p. 120)

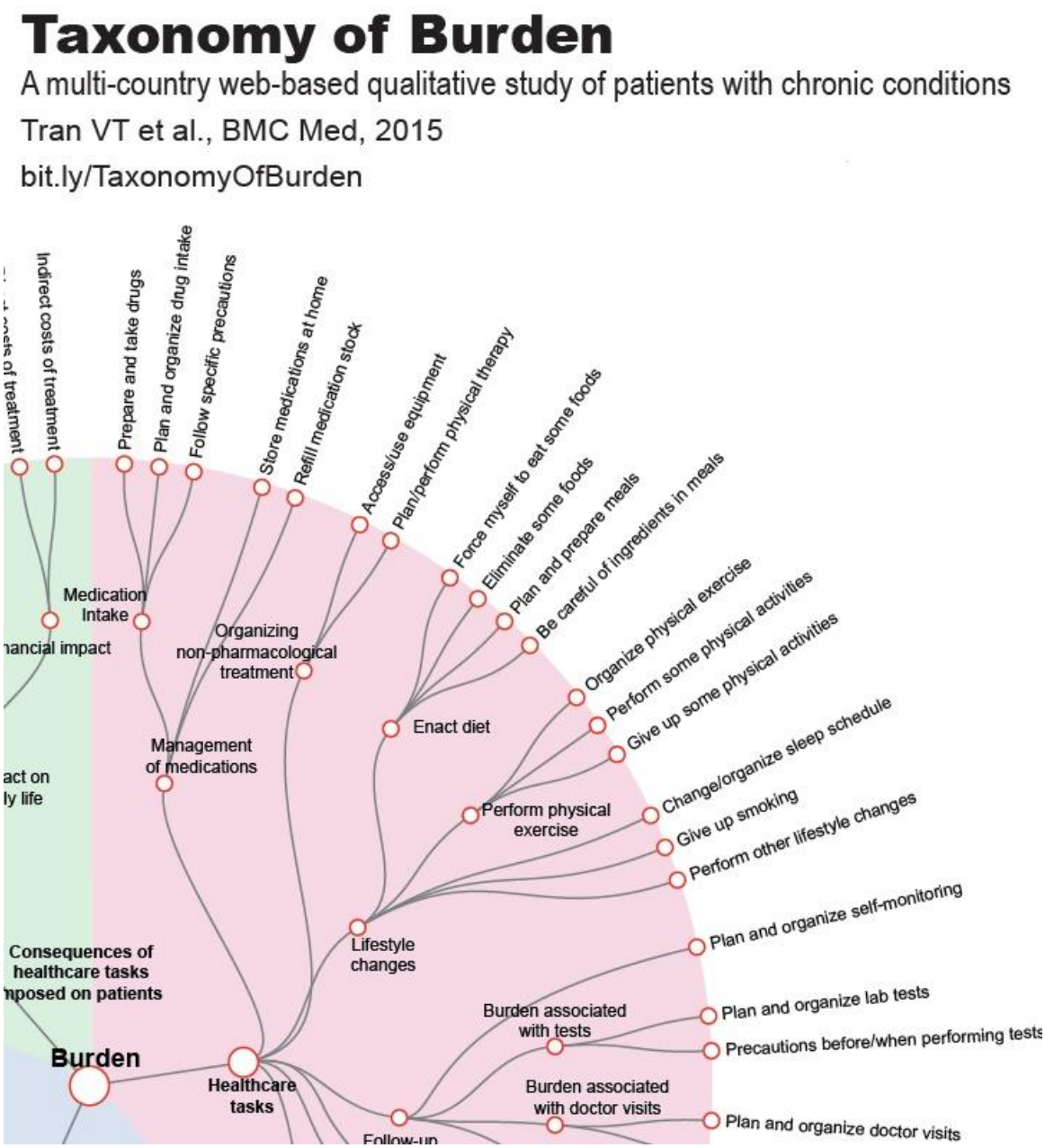

Figure 4: Detail from Taxonomy of the Burden of Treatment (Tran, Barnes, Montori, Falissard & Ravaud, 2015, p. 120)

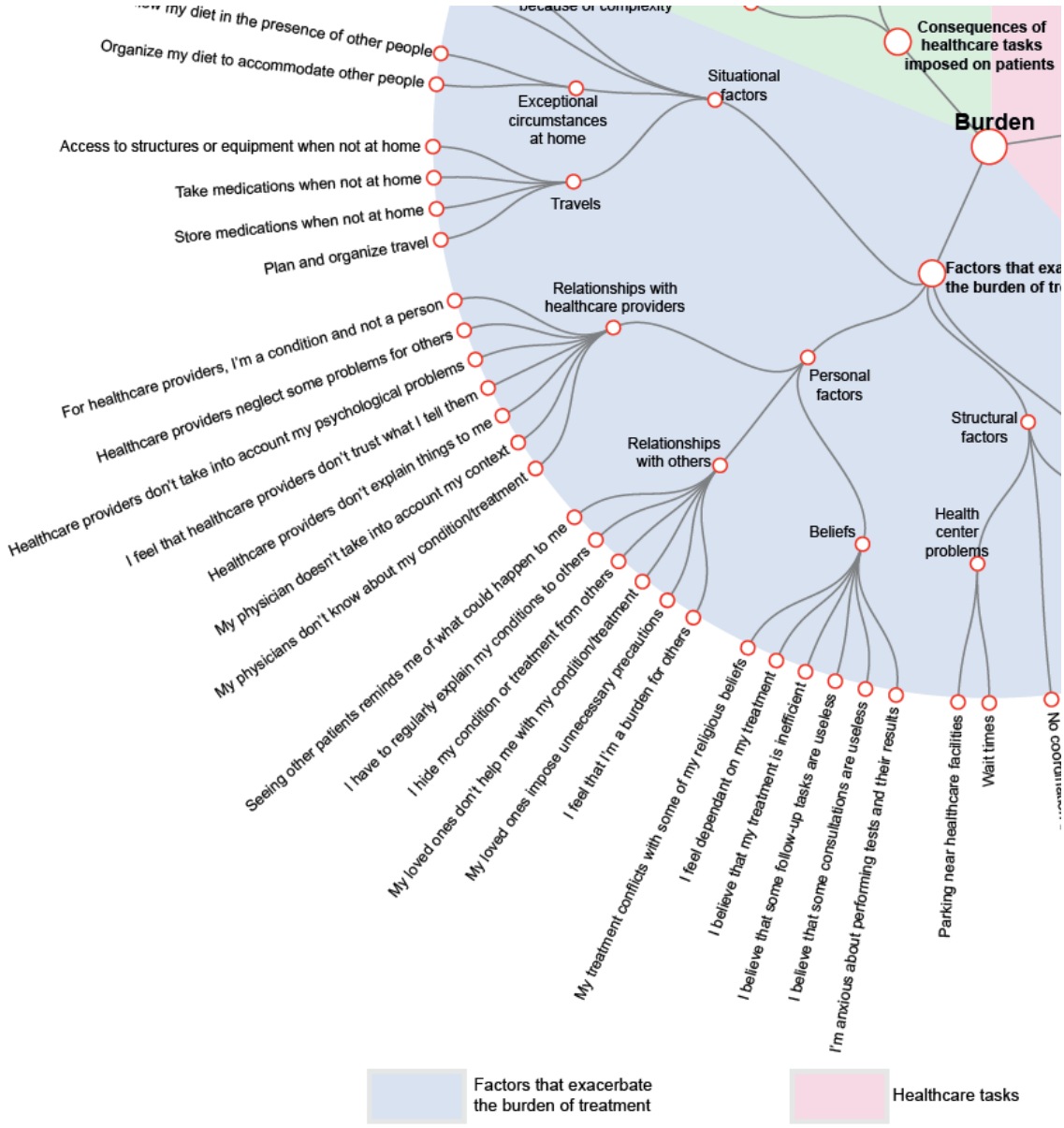

Figure 5: Detail from Taxonomy of the Burden of Treatment (Tran, Barnes, Montori, Falissard & Ravaud, 2015, p. 120)

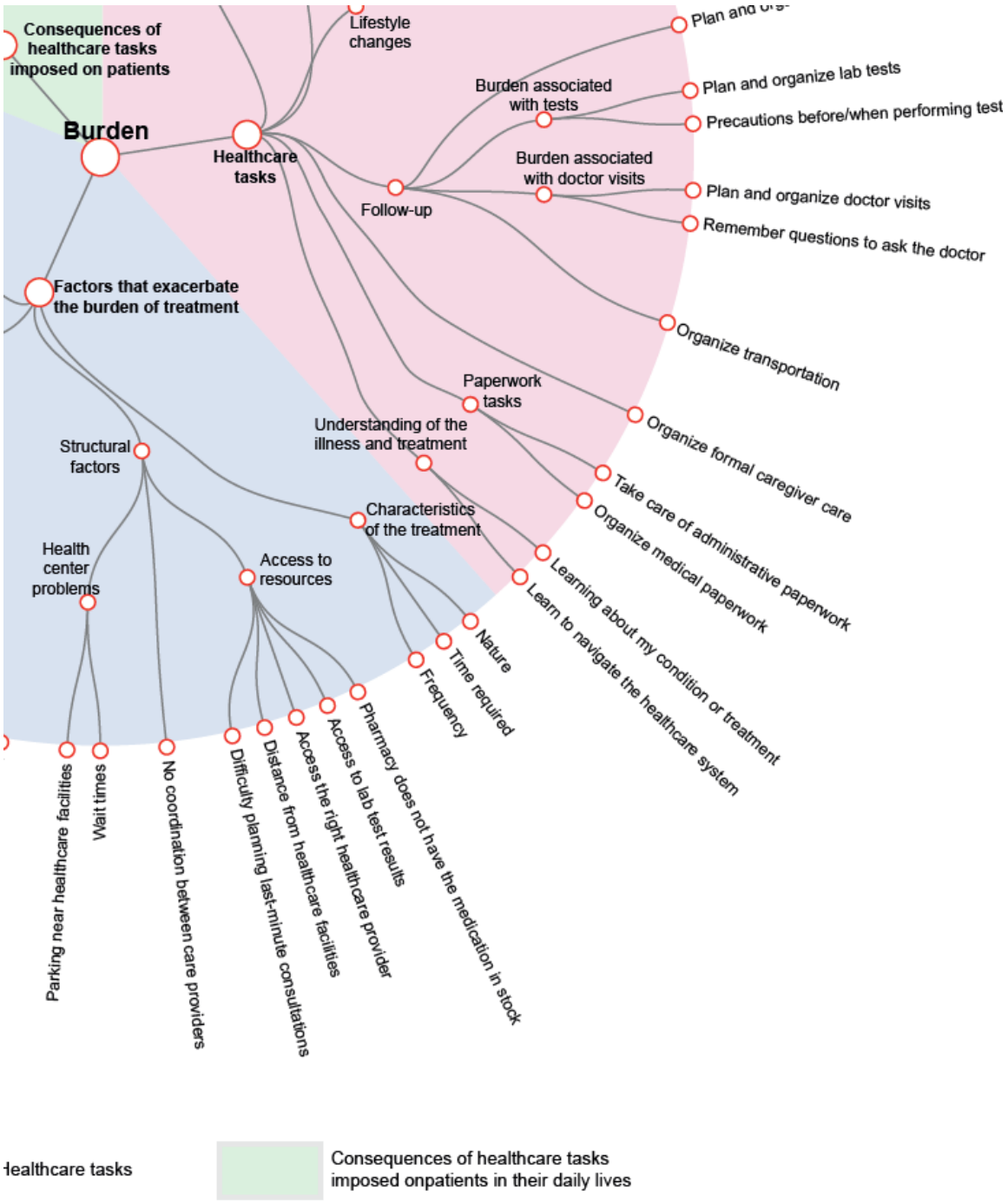

Figure 6: Detail from Taxonomy of the Burden of Treatment (Tran, Barnes, Montori, Falissard & Ravaud, 2015, p. 120)

Appendix H: Excerpt from Data Analysis

The following is the detailed analysis of an extract from the interview with Beth. It covers 5 minutes from a total of 66 minutes duration of the interview.

Table 2: Extract from Working Analysis of Beth's Interview

Original Transcript in Maltese	**English Translation of Transcript**	**Exploratory Notes**	**Emergent Themes**
Participant (P). Eżatt. U jiena bilħaqq il-chemos l-oħra kollha d-day ward ħadthom. Hemmhekk anġli wkoll iġifieri.	Exactly. And by the way I took chemos at day ward. The staff are all angels there too.		P's positive description of the health services. Individual attention to P.
Researcher (R). U int trid tigi spiss nimmaġina bħala appuntamenti?	And you needed to come frequently for appointments right?		
P. Kull 3 ġimgħat. Għax mbagħad tarak it-tabiba qabel il-chemo	Every 3 weeks. As then the doctor sees you before the chemo.		Frequent link with hospital.
R. Trid tiġi għad-demm ukoll?	You need to come for bloods?		
P. Niġi jumejn qabel għad-demm.	I come 2 days before for bloods.		
R. Dik kif tara? Il-fatt li trid tiġi spiss bejn treatment u ieħor?	How do you see the fact that you need to come frequently in between treatments?		
P. Le ta ma naraħhiex, anzi, kultant inkun nixtieq li jkun iktar fil-qrib għax iktar tħossok safe.	Fine for me, actually at times I wish it to be so as I feel safer this way.		Trust in health services. Frequent link for P is reassuring.
R. Allright.	All right.		
P. Qed tifhem? U ħaġa oħra .. Jiena meta nkun ħadt il-chemo u jitlagħli d-deni d-dar, nkunu rridu niġu l-emerġenza, l-emerġenza vera iġifieri jagħtuk servizz, u jibdewlek minn fuq s'isfel testijiet li kien	Do you understand? And something else, when I take chemo and I get fever and I am home I would need to get to A & E. At A & E they treat you very well and they do all the tests from scratch; now the last	The risk of fever is high with cancer patients thus the probability of needing an A&E visit is a reality; however the health system does not have a protocol to	P's description of health services; a gap in health systems' information. Anxiety and frustration at starting afresh with hospital every time

hemm fil-bidu, issa l-aħħar li mort aħjar (sarkastika), ma kellhomx aċċess għall-file tiegħi mill-Emerġenza għallura riedu joqogħdu jsaqsu lili x'ħadt u x'ma ħadtx , l-istorja mill-bidu ..	time I went it was even better (sarcastic) as the medics did not have access to my file from Emergency so they had to stay asking me my medical story with the treatment taken etc, my story from the beginning ..	manage it; never sure what the process of admission will be.	and telling her story over and over again.
R. Ilaħwa.	Oh my!		
P. U mbagħad daħħluni ġo ward li dawn ikunu speċjalisti per eżempju, tal-kliewi, għax huma jitfgħuk fejn hemm post.	And then they admitted me in a ward, a specialist ward, for eg the Renal ward as they put you were there is a bed.		Traumatic illness experience made worse by the health system set up.
R. Bhala Mater Dei qed tgħid bħala ward?	As in MDH ward?		
P. Bħala Mater Dei. Hemm, dik biss li kien hemm naqra .. U anke li kieku ċ-ċentru tal-onkoloġija kien ikbar .. Aħna għall-emerġenza tagħna m'għandniex għalfejn immorru Mater Dei. Kieku niġu hawn mill-ewwel għax il-problema tkun related mal-chemo.	Yes as MDH, that is the only think I find bad .. and even had the OC been larger .. our emergency needs to be at the OC, we won't need to get to MDH as the admitting problem would be related to chemo.	The concern raised by P on the process of A&E admission came across very clearly.	Anxiety felt in the links with hospital system.
R. Eħħe.	Ehhe.		
P. Dik biss. Imma l-bqija ..	That's the only thing, otherwise.	P. kept repeating the concern on A&E admissions of cancer patients.	Positive description of the health services in spite of the hastles experienced
R. Iġifieri kieku tkun, meta tkun ċara li hija relatata mal-chemo jew mal-effetti ..	So if the problem would be clearly linked to chemo or its effects ..		
P. Dejjem hekk ikun hu ..	It is always so ..	Very clear for P. that the solution for cancer patients is a different arrangement of hospital admission to what exists at present.	

R. Fil-kaz tiegħek, għax mhux kull sitwazzjoni imma jkun hemm. Kultant tkun diffiċli tgħid ukoll. Imma ..	In your case yes; not every situation is so clear, however ..		
P. Ukoll eħħe.	Yes		
R. Iġifieri li kieku hemm sistema differenti, inti l-feedback tiegħek fuqha x'ikun?	Had there been a different system, what would be your feedback on it?		
P. Le li jkun hawn emerġenza fl-oncology jew għalmenu ..	That there would be an Oncology A&E at the OC or at least ..	Conversation brought out the numerous times P. experienced admission to hospital with frequent need to have to tell her illness story over and over again; very concerning for Beth.	P's experience of the health systems got her to recommend a specialised admission to Oncology for palliative situations.
R. X'effett tagħmillek kieku inti? Kieku hemm dak is-servizz?	What would be your feedback had there to be this service?		
P. Kieku tkun iktar .. għax .. meta tkun inti ġo ward oħra tant huma caring li huma joqogħdu jagħmlulek it-testijiet ta' x'qed jaħsbu li huma, jista' jkun related ma l-affarijiet ..	It would be much better .. because when you are in a MDH ward they are so caring that doctors keep doing all investigations of what they think is wrong but ..	Such gap in health systems' information is a costlier affair for the health system	P positively describes the health systems in spite of the gap in health systems' information
R. Eħħe, kundizzjonijiet oħra ..	Other conditions ..		
P. Eżatt, jiġifieri qed jieħdu x-xogħol huma ta' Mater Dei. U mbagħad huma kemm jikkomunikaw mal-oncologist.	Exactly, which means that MDH staff are doing a lot of extras. And they need to link with the oncologist.	P emphasised the vital link with the Oncologist; she had to emphasise such link in some of her MDH admissions thus there is no clear protocol.	P's description of health services; a gap in health systems' information
R. U dik in ġenerali sibtha? Li l-kommunikazzjoni ssir mal-oncologist?	And did you find that link, the communication with the oncologist?		

P. Iva iva issa qed issir. U bl-email jiġifieri. L-onkoloġista twieġeb mill-ewwel.	Yes now it's taking place. And via email. The oncologist replies immediately.	Link with this oncologist is more systematic but in past months.	P's description of health services; a gap in health systems' information.
R. Innutajt differenza? Għall-bidu, 3 snin ilhu, bħala kommunikazzjoni fuq is-servizzi differenti?	Did you notice a difference? At the beginning, 3 years ago, the communication from the different services?		
P. Ifhimni ..	Well ..		
R. Għax inti għaddejt minn ħafna servizzi. Mhux kollha hawn, anke Mater Dei. X'tgħid fuq il-kuntatt? Dak il-link?	Because you have experienced a lot of services and ward, even at MDH. What do you say about that contact? That link?		
P. Le, tajjeb. Imma fil-bidu kien hemm per eżempju kif qegħdin ngħidu: l-emerġenza ma jafux, u anke fejn jitfgħuni. Imma mbaghad ngħidilhom speċi kkuntatjaw lill-onkoloġista u bdew jagħmlu hekk. Qed tifhem?	Good however in the beginning there was lack of information, for example at A & E, and even in which wards I was admitted. But then I started telling them to contact the oncologist and the medics started doing that. Is it clear?	P is steering her cancer illness management by emphasising the link admission team needs to initiate with specialist; an obvious link but not done in practice.	P's description of health services; a gap in health systems' information. P learnt how to s steer around this gap and it is working better for her.
R. Mhm, mhm.	Yes.		
P. U mill-ewwel twegibhom. Għax huma xorta jridu jinfurmawha li jiena qiegħda Mater Dei.	And the oncologist replies immediately. Because the doctors still need to inform the oncologist that I am at MDH.		P has trust in health services; however essential link with specialist is not formalised.
R. Mhm. Dik x'effett tħalli meta qishek jassigurawk li għamlu dak il-kuntatt ma' min l-iktar li jifhem fis-sitwazzjoni tiegħek?	I see. What effect does that leave you with when the medics reassure you that they have made contact with the specialist that most understands your medical situation?		
P. Mela. Dik qisha l-mummy tiegħi jien, qed tieħu ħsiebi. Għallura lilhom .. Anzi issa sirt li ħallewni ma' professor wieħed u kull darba li	A lot. She is like my mother to me, she takes good care of me. So very good.. now even better because MDH have kept me with the	The choice of words in this case where the oncologist is described as "my mummy" is heavily	Reassuring for P once essential link with specialist is done

nidħol l-emerġenza naqa' taħthu. Għalmenu dak jaf, imma qabel ma kinitx hekk.	same MDH consultant for every admission. So now he knows my medical story, before it wasn't like that at all.	laden as the P has a very trusting relationship with her own mother who has been there throughout all her treatment regimes, abroad and locally, and still is present in her illness journey; equating the oncologist to all this is weighty. The ad hoc system adopted in P's case should be explored further as, without challenging the MDH system too much, it could provide a workable system, decreasing the investigative workload and, most importantly, creating a smoother, a more reassuring set up for Palliative patients.	"qisha l-mummy tieghi"; "she's like my mummy" Health system developed an hoc set up in the present system where P has a "fixed" consultant at MDH as well as in Oncology; very reassuring for P
R. Skont min tinzerta?	It depended on who you were admitted under?		
P. Qabel kienet skont min tinzerta, għallura trid toqgħod tgħid kollox mill-bidu terġa'.	Yes before it depended on the consultant I was admitted under and thus I had to stay repeating my story all over again.		P's description of health services; a gap in health systems' information
R. U din bħala sistema sibtha aħjar? Iġifieri minkejja li tmur Mater Dei, il-fatt li ..	And you found the system that was adopted for you better?		
P. Li ħallewni ma' l-istess professor, dik sibtha aħjar. Għax issa hu qed jibni qisu l-history tiegħi, u meta nidħol ikun jaf għal xiex ħa jfittex, qed tifhem?	That they left me under the same consultant much, much better. He is now building a history of my medical situation, and in a MDH admission he knows what to investigate etc		Reassurance with being admitted under same consultant. Flexibility in system.

R. Mhux għadek fil-bidu, trid toqgħod terġa' tispjega l-istorja.	And it is not like you are a new patient everytime and I need to explain my medical situation all over again.		
P. Eżatt, u għandi communication mal-onkoloġista wkoll, biex mhux ikun hemm ħafna ..	Exactly, and there is communication with the oncologist too, so that there are not a lot of … (gaps)		P. put her mind at rest at being admitted under same consultant. Communication among the different sections

Appendix I: Institutional Approval of Research

I1. Oncology Centre

SIR ANTHONY MAMO ONCOLOGY CENTRE

FORM :	**Oncology Proposal/Approval Audit/ Research purposes**
Document Code: ONCO-GeFO-P/A-001. Ver.01	Reference SOP : ONCO-Ge-PD.AP--001.Ver.01

Clinical Consultant Oncologist/s:
Name and Surname (in block letters) and Signature

Dr Stephen Brincat

Dr Claude Magri

Dr Rachel Micallef

Dr Nick Refalo

Dr Doreen Pace DPACE 2026.

Heads of:
(Name, Surname and Section (in block letters) and Signature)

Radiotherapy Department: ***(if applicable)***

Radiography

Medical Physics

Nursing

Other SAMOC Departments/ Wards:

Clinical Support Services, Onc Centre **Ms Corinne Fiorini, Sen Allied Health Prof**

~~Dr. Berina Chase Dpsych~~
Clinical Psychologist
Clinical Support Services
~~Sir Anthony Mamo Oncology Centre~~
Principal Psychologist MP PB 001

Clinical Chairperson (Haematology - Oncology): Dr Stefan Laspina
Name and Surname (in block letters) and Signature:

Dr. Stefan Laspina
Clinical Chairman
Department of Haematology & Oncology

Quality Assurance Manager:

Name and Surname (in block letters) and Signature: Mr Edward Falzon

An approval is granted to carry out the study/audit at any SAMOC Department. Patient information can be accessible only by complying with the following data protection principles, which are set out in the Data Protection Act 2001. In summary these state that patient's data shall:

- ***Be obtained and processed fairly and lawfully and shall not be processed unless certain conditions are met. Therefore patient's information (including scans) should be made anonymous by an appointed radiotherapy staff (from the Head of section)***
- ***Be obtained for a specified and lawful purpose and shall not be processed in any manner incompatible with that purpose.***
- ***Be adequate, relevant and not excessive for those purposes (in the case of a study or audit).***
- ***Be accurate and kept up to date.***
- ***Not be kept longer than is necessary for that purpose***
- ***Be processed in accordance with the data subject's rights.***
- ***Be kept safe from unauthorised access, accidental loss or destruction.***
- ***Not be transferred to any third party unlawfully.***

I2. Mater Dei Hospital

The cancer pts lived experience of the Health system in Malta

MATER DEI

Information Management & Technology Department
Mater Dei Hospital
Telephone: 2545 5346

POLICY ON ACCESS TO PATIENT DATA
ON MATER DEI HOSPITAL (MDH) SYSTEMS

Access to patient data recorded on MDH systems, whether in paper or electronic form, is permitted solely for the purpose of delivering or supporting delivery of health care, as part of the performance of official working duties.

All patient data on MDH systems is 'personal data' or 'personal sensitive data' in terms of the Data Protection Act. Therefore, access to patient data is subject to compliance with the provisions of the Data Protection Act, as well as those of the Professional Secrecy Act and other relevant legislation and regulations, including the computer misuse provisions of the Criminal Code.

Person identifiable patient data may not be copied, oriented or otherwise exported from MDH-based systems (paper or electronic) except as part of the performance of official working duties.

DECLARATION ON ACCESS TO PATIENT DATA

I hereby declare that I will respect the confidentiality and privacy of any personal data or information that I will come across at Mater Dei Hospital or on Mater Dei Hospital systems and will in no circumstance disclose any such information to third parties not directly involved in the patient's care without the patient's prior and informed consent.

I also declare that I am aware of the provisions of the Data Protection Act (ref: http://justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=8906&l=1), the computer Misuse provisions of the Criminal Code (ref: http://justiceservices.gov.mt/DownloadDocument.aspx?applom&itemid=8574&l=1), and the Professional Secrecy Act (ref: http://justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=8844&l=1), and that I will abide by all Government and hospital regulations related to data, information and use of IT systems and services (ref: http://ictpolicies.gov.mt , http://www.kura.gov.mt).

Signature:
Full name: CHRISTINA CALEA CURMI
ID / Passport number: 59568 (M)

INFORMATION MANAGEMENT & TECHNOLOGY DIRECTORATE MATER DEI HOSPITAL MSD 2090

25.5.18

FRECFHS_1718_117

To be completed by Faculty Research Ethics Committee

We have examined the above proposal and advise

Acceptance **Refusal** **Conditional acceptance**

For the following reason/s:

Signature Date 2/07/2018

To be completed by University Research Ethics Committee

We have examined the above proposal and grant

Acceptance **Refusal** **Conditional acceptance**

For the following reason/s:

Signature Date