

The Dignity of Patients with Palliative Needs: Patients' and Family Caregivers' Perspective in Lebanon

Silva Dakessian Sailian

Master's in Public Health

This thesis is submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy. The candidate has already achieved 180 credits for assessment of taught modules within the blended learning PhD programme

May 2022

Faculty of Health and Medicine
Lancaster University

I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere

Abstract of the Thesis

Introduction

Preserving patient dignity is an overarching tenet in palliative care. Though patient dignity and its multiple facets have been studied in Western societies, interpretations of dignity may change depending on the context influenced by socio-cultural, and political circumstances, ensuing in different meanings and implications.

Aim

To explore the interpretations of the concept of dignity perceived by patients with palliative care needs and family caregivers within the Lebanese context.

Method

1. An integrative review to explore and synthesise evidence on the understanding of dignity in the Middle Eastern palliative care context.
2. A qualitative interview study with fourteen patients with palliative needs and fifteen family caregivers to understand how dignity is interpreted and preserved in illness. The data were analysed inductively using reflexive thematic analysis. The findings from the two groups of participants were compared against each other and with the Chochinov Model of dignity.

Findings

Most of the findings from the integrative review came from Iran. Seven themes were developed: Maintaining privacy and secrecy; Gentle communication to preserve hope for wellbeing; Financial stability and accessibility of medical supplies; Family Support; Physical Fitness; Reliable health care, and Social justice that endorses equal care to all. Patients' and family caregivers' interviews revealed four common themes about maintaining dignity: a) The importance of faith b) The need to preserve physical, social, and mental wellbeing c) The central role of family d) Compassionate health care. These findings were similar to the themes synthesised from the integrative review highlighting the impact of context in understanding dignity. When comparing the findings to the Chochinov Model of Dignity, *preserving outer physical appearance, equitable and affordable care and health resources* were two new subthemes that surfaced as necessary for maintaining dignity during illness. Faith and family support emerged as central findings anchoring patient dignity. On the other hand, *Autonomy and Aftermath concerns*, themes mentioned in the Chochinov Model, appeared to be of less importance in this participant group.

Conclusion

In contrast to Western countries, faith and family ties in Lebanon are central in understanding and maintaining dignity for patients with palliative needs. This study demonstrates that cultural values and the overall socio-economic and political environment shape patients' interpretations of dignity, resulting in implications for policy, clinical practice, community initiatives, and education.

Acknowledgements

The journey of attaining this PhD degree has not been easy to accomplish. As I arrive at its end, I would like to express my heartfelt gratitude to a few people without whom this endeavour would not have been actualised.

First, my humble gratitude and acknowledgement to God's embracing support who arranged events, people, and timing, in a delicate way to fulfil my dream of attaining a PhD. I am indebted to my dear husband, Johnny, for his impartial judgment, patience, and unwavering support - emotionally and practically - to accomplish this expedition despite various challenges and family responsibilities. Thank you for spending so many nights sleeping on the couch waiting over while I work on my computer.

I want to express my gratitude to my university, the American University of Beirut (AUB), who endorsed this project and facilitated its sponsorship.

Of course, the success and the uniqueness of this PhD thesis would not have been possible without the continuous guidance and the vision of my stellar supervisors, Professor Nancy Preston, and Dr. Yakubu Salifu. They were my role models and source of motivation assisting me to overcome difficult phases and troubled times through compassionate support and close guidance. They successfully transformed these five years into years of growing and evolving into a better version of me.

I also owe the realisation of this research to the participants who accepted to take part in the study despite the challenging times of Covid-19, the dire living conditions, and the 2020 port explosion in Lebanon. Finally, thanks to my tutor, Dr. Amanda Bingley for her valuable guidance in the early phases of my studies, and my special friends, Jackie and Krystina who, though far away, were always generous with their time and cheering.

This work is dedicated to the memory of my father-in-law, Zaven Sillian, who passed away suffering in an ICU bed in April 2020. I hope the future of Lebanon holds a change in delivering quality palliative care preserving the dignity of patients.

Table of Contents

THE DIGNITY OF PATIENTS WITH PALLIATIVE NEEDS: PATIENTS' AND FAMILY CAREGIVERS' PERSPECTIVE IN LEBANON	1
ABSTRACT OF THE THESIS	2
ACKNOWLEDGEMENTS	3
TABLE OF CONTENTS	4
LIST OF TABLES	7
LIST OF FIGURES	7
CHAPTER 1. INTRODUCTION	8
1.1 THE RESEARCH CONTEXT	8
1.2 AIM AND FOCUS	9
1.3 NEED FOR THE RESEARCH	10
1.4 THE BACKGROUND OF THE RESEARCHER	11
1.5 SUMMARY OF THE METHODOLOGY	11
1.6 CONTRIBUTION TO KNOWLEDGE	12
1.7 THE ORGANISATION OF THE THESIS	13
CHAPTER 2. BACKGROUND	16
2.1 THE SOCIO-POLITICAL STATE AND HEALTH SYSTEM IN LEBANON	16
2.2 GOVERNMENT MISMANAGEMENT AND TRIPLE CRISIS	20
2.3 THE STATE OF PALLIATIVE CARE IN LEBANON	21
2.3.1 <i>The Effect of Covid-19 Pandemic on Palliative Care in Lebanon</i>	25
2.4 EVOLUTION OF THE CONCEPT OF DIGNITY	26
2.5 DIGNITY IN ILLNESS AND IN PALLIATIVE CARE	28
2.6 THEORIES ABOUT DIGNITY	31
2.7 CONCLUSION	36
CHAPTER 3. HOW IS DIGNITY UNDERSTOOD AND MAINTAINED IN PATIENTS WITH PALLIATIVE NEEDS IN THE MIDDLE EAST? AN INTEGRATIVE REVIEW	38
3.1 INTRODUCTION	38
3.2 THE REVIEW QUESTION AND AIM	39
3.3 REVIEW METHOD	40
3.3.1 <i>Problem Identification</i>	41
3.3.2 <i>Literature Search</i>	41
3.3.3 <i>The search strategy</i>	42
3.3.4 <i>Inclusion-Exclusion Criteria</i>	44
3.3.5 <i>Search Outcomes & Data Extraction</i>	48
3.4 DATA EVALUATION	51
3.5 DATA ANALYSIS	51
3.6 FINDINGS	52
3.6.1 <i>Characteristics of the studies</i>	52
3.6.2 <i>Themes</i>	63
3.7 DISCUSSION	77
3.8 STRENGTHS AND LIMITATIONS	80
3.9 CONCLUSION	81

CHAPTER 4. METHODOLOGY	82
4.1 INTRODUCTION	82
4.2 PHILOSOPHICAL POSITION: EPISTEMOLOGY AND ONTOLOGY	82
4.3 WHY QUALITATIVE METHODOLOGY?	86
4.4 REFLEXIVITY	87
CHAPTER 5. METHODS.....	90
5.1 DATA COLLECTION METHODS	90
5.1.1 <i>Sampling</i>	90
5.1.2 <i>Recruitment</i>	<i>Error! Bookmark not defined.</i>
5.1.3 <i>Informed Consent</i>	95
5.1.4 <i>The Interview</i>	97
5.1.5 <i>Research ethics</i>	101
5.2 DATA ANALYSIS	101
5.3 QUALITY ASSURANCE	104
5.4 CONCLUSION	ERROR! BOOKMARK NOT DEFINED.
CHAPTER 6. THE FINDINGS FROM THE PATIENTS' INTERVIEWS	107
6.1 PARTICIPANTS.....	107
6.2 THEMES.....	109
6.2.1 <i>Theme One: Faith 'I have my faith you know... whatever will happen will happen'</i>	111
6.2.2 <i>Theme 2: Family and Children 'Thank God I have my Children'</i>	114
6.2.3 <i>Theme 3: Physical, Social and Mental Wellbeing' changed upside down...'</i>	118
6.2.4 <i>Theme 4: Compassionate & Comprehensive Care 'The physician kissed me on the forehead and told nothing is wrong with me'</i>	122
6.3 SUMMARY	128
CHAPTER 7: FINDINGS- FAMILY CAREGIVERS' PERSPECTIVE	130
7.1 PARTICIPANTS.....	130
7.2 THEMES.....	132
7.2.1 <i>Theme 1: Duty 'Only kindness and sweetness are my duty towards him'</i>	134
7.2.2 <i>Theme 2: Securing a good quality of life 'Make sure all patient's needs are met'</i>	138
7.2.3 <i>Theme 3: Maintaining the role in society 'My father is still the caretaker of the family'</i>	142
7.2.4 <i>Theme 4: The role of the health service in maintaining dignity 'The approach of nurses was more than giving meds'</i>	145
7.4 SUMMARY	150
CHAPTER 8- DISCUSSION	152
8.1 INTRODUCTION	152
8.2 SUMMARY OF THE FINDINGS	154
8.3 COMPARING THE PATIENTS' & FAMILY CAREGIVERS' PERSPECTIVES ON DIGNITY.....	155
8.3.1 <i>The Similar themes</i>	156
8.3.2 <i>Themes that diverged in patients and family caregivers' perceptions</i>	164
8.4 EVALUATING THE FINDINGS AGAINST THE CHOCHINOV MODEL.....	165
8.4.1 <i>Categories of the Dignity Model</i>	167
8.5 SYNTHESIS OF THE FINDINGS	174
8.6 PERSONAL REFLECTION	176
8.7 IMPLICATIONS TO PRACTICE, POLICY, AND RESEARCH	179
8.7.1 <i>Implications for practice:</i>	179

8.72 <i>Implications for Policy:</i>	181
8.7.3 <i>Implications for research:</i>	182
8.8 STRENGTHS AND LIMITATIONS.....	186
8.9 CONCLUSION	187
APPENDICES	208
APPENDIX A.....	209
APPENDIX B.....	213
APPENDIX C.....	216
APPENDIX D.....	217
APPENDIX E	218
APPENDIX F	221
APPENDIX G.....	224
APPENDIX H.....	227
APPENDIX I	230
APPENDIX J.....	231
APPENDIX K.....	233
APPENDIX L	235
APPENDIX M.....	236

List of Tables

Table 3. 1 SPICE Framework.....	41
Table 5. 1 Inclusion & Exclusion Criteria	91
Table 5. 2 The Analysis.....	103
Table 6.1 Participant Demographics	109
Table 6. 2 Themes and supporting sub-themes.....	111
Table 7. 1 Participants' Characteristics.....	131
Table 7. 2 Themes.....	134
Table 8. 1 Recommendations to preserve patient dignity in palliative care.....	184

List of Figures

Figure 2. 1 The adapted Dignity Model by Chochinov (Chochinov et al, 2002).....	34
Figure 3. 1 PRISMA Flow Diagram of the review process	50
Figure 5. 1 The thematic mapping of the themes and subthemes	110
Figure 6. 1 Thematic mapping of the findings.	133
Figure 8. 1 Position of the Lebanon adapted from the Inglehart-Welzel World Cultural Map - World Values Survey (2020)	154
Figure 8. 2 Chochinov's Model of Dignity (2002)	166
Figure 8. 3 Chochinov's Dignity Model adjusted in light of the new findings.....	173
Figure 8. 4 The Dignity Flower / Lotus.....	175

Chapter 1. Introduction

1.1 The Research Context

What captured my attention in palliative care is its new and enticing ethos that considered a revolutionary movement in the field of medicine. Palliative care is practiced by very few health care professionals in Lebanon adding a much-needed layer of compassionate care through its holistic approach (Osman, 2015). I was lucky to be working in an academically affiliated health institution in Beirut where palliative care services existed in a reserved manner. A three -member hospital-based team consisting of a doctor, a nurse, and a psychologist visited the patients who were dying to provide support a few days before their death upon referral from their primary physician. I was captivated by the work of palliative care team because it was emancipatory as it sought to reduce suffering in patients with serious incurable illnesses regardless of age, gender, or diagnosis, aiming to improve the day to day living amid hopelessness (Radbruch et al., 2020; WHO, 2020). The conversations about end of life and death by the palliative team somewhat defied the standard norms and pride in medicine that resisted the notion of mortality, regarding it a medical failure (Exley, 2004; Lancet, 2018; Rosenberg, 2011). As a clinical nurse instructor who spent some time on the ward with students, I learned how the palliative care team was humbly and elegantly tackling issues which were intimate and important for the patients. The palliative team addressed their needs: how to sleep better, to manage incontinence, and what meals are easily digested. All this was done with kindness, understanding, validating patient concerns, and preserving dignity in day-to-day living (Kennedy, 2016). I realised how dignity was fragile and at risk in patients with

serious illnesses, under the impact of complex symptoms that caused a deviation from normal and left them demoralised from their incurable condition (Chochinov, 2006; Van Gennip et al., 2013). Against this reality, palliative care addresses the ‘total pain’ of patients that active medical treatment tends to shy away from. Palliative care reframes caring by individualising care, allowing patients and families to take an active role that resonates with the patient specific narrative maintaining their dignity (Clark, 2014). From these reflections, I developed an enthusiasm to explore the finest of human values, the concept of patient dignity within the palliative care context in Lebanon.

1.2 Aim and Focus

The aim of this research is to explore the interpretation of the concept of dignity in adult patients with palliative care needs and family caregivers in Lebanon. Dignity is ‘the quality or state of being worthy, honoured, or esteemed’ (Merriam-Webster online, 2018).

The concept of dignity and dignity promoting interventions in palliative care has been well debated and analysed in the Western literature, however, it remains minimally assessed in the Middle Eastern setting, leaving the utility of the Western literature and recommendations uncertain. Though dignity is a universal human need, it is a value charged phenomenon which is highly contextual. The meaning of dignity needed to be defined from the viewpoint of the Eastern Mediterranean part of the world, and compared to the existing literature (Kadivar, 2018). To achieve the aim, the study had four objectives:

- A) Explore the interpretations of the concept of dignity in patients with palliative needs as perceived by patients and family caregivers.

- B) Examine how dignity is experienced while receiving health services in adult patients with palliative needs.
- C) Assess how family caregivers perceive and preserve the dignity of their relatives with palliative needs during illness and while receiving health care services.
- D) Critically assess and compare the findings of the research in relation to Chochinov's Dignity Model.

1.3 Need for the Research

Palliative care is underdeveloped in Lebanon and delivered through a few charitable organisations and some large tertiary hospitals (Osman, 2015). Though Lebanon has the fastest ageing population in the Arab region (ESCWA, 2021a) with high rates of non-communicable diseases (Soueidan, 2018), various challenges hinder the effective delivery and integration of palliative care in its mainstream health services (Daher et al., 2008).

To improve palliative care practice in Lebanon, evidence-based research that reflects native culture and needs is essential. Exploring the concept of dignity, and the actions or conditions that protect or harm dignity in patients with palliative needs, would be a starting point for widening insight and propose strategies to promote patient dignity. No studies exist which explore dignity in Lebanon, so the intention of this study was to generate original knowledge that would be useful in understanding the fundamental concept of dignity in patients with palliative needs and family caregivers, and maybe guide clinical and community practice.

1.4 The background of the researcher

To explain my position to the reader and enhance transparency, I describe my different roles that may have affected the selection of the topic, research design, and interpretation of the findings. The PhD training opened the window for multiple reflective moments that made me realise how my career as a nurse and a nursing instructor, my religious worldview that focused on kindness, and my societal expectations have impacted my perspective and behaviour. This research was conducted during the corona virus (Covid-19) pandemic, amid the immense socioeconomic decline in Lebanon where overall suffering, hardship, and inequity had soared. The restricting conditions enacted due to the Covid-19 pandemic, the extremely volatile socio-political situation in Lebanon compounded by the Beirut port gas explosion in August 2020, have left their mark throughout the research phases slowing its progress and affecting participant responses. Living through these challenges as a nurse, instructor, a caregiver, a mother of three children, and the painful death of my father-in-law, has strengthened my determination to advocate for palliative care, with the aim of increasing patient dignity and awareness of palliative care in my community.

1.5 Summary of the methodology

An integrative review was conducted first to explore and synthesise the concept of dignity in palliative care in the Middle Eastern setting. Then I conducted the research using a qualitative design influenced by social constructionism. Qualitative methodology is ideal to investigate human experiences and unveil participant perspectives and meaning attributed to phenomena such as patient dignity (Creswell, 2009). The data were collected

through in-depth interviews of adult patients with advanced chronic or terminal illnesses and family caregivers via telephone calls. In person interviews were carried whenever circumstances allowed, applying protective precautions to prevent Covid-19 transmission. The interviews of patients and family caregivers were analysed inductively using reflexive thematic analysis (Braun & Clarke, 2020). The findings from both groups of participants, patients, and family caregivers, were compared to the integrative review, the wider international literature, and the empirical model of dignity (Chochinov, 2002). Assessing the findings against the Western literature, particularly an established model of dignity, was regarded as essential to understand the impact of context on experiences of dignity, gaining insight into sociocultural, economic, and political factors that shape perception and life of dignity in palliative care.

1.6 Contribution to Knowledge

This thesis makes several contributions to the understanding of the concept of dignity in palliative care settings. First, it illuminates the differences in the interpretations of the experience of dignity in patients with palliative care needs, from a diverse cultural background providing a non-Westernised perspective. The findings unveil how dignity and wellbeing is dependent on the overall social, political, cultural, economic, ecological, and spiritual factors, that shape patient needs, perceptions, and experiences of dignity (Folke et al., 2016). This thesis uncovers how social and cultural capital, such as family, traditions, and religion, provide patients with support and grounding for dignity. Family caregivers, who are actively involved in the care of the patient, and spiritual faith, constitute the platform for a safe and a dignified living for the palliative care patient. The

findings highlight the importance of relationships and the feeling of connectedness as a precondition to preserving dignity. These relationships assist the patient to access health services and secure vital resources, thus preserving dignity. The multiple layers that represent the essence of dignity for patients with palliative needs is articulated by synthesising a model, the 'flower of dignity' (see chapter 7).

The findings generate recommendations that could be referred to by health providers, clinicians, communities, families, health educators, key society leaders and policy makers in introducing change, devising interventions, policies, and creating communities and social circumstances that affirm and promote patient dignity in advanced and terminal illness.

1.7 The Organisation of the Thesis

The thesis is composed of seven chapters.

Chapter 1: Introduction. The chapter provides an overview of the research topic, states the aims, the context, the design, and the contribution this thesis make to knowledge. It also states the impetus for selecting the subject of patient dignity highlighting the researcher's background.

Chapter 2: Background. This chapter describes the social and political setting and the state of palliative care in Lebanon. It touches upon the ethos of preserving patient dignity in palliative care amid serious illness. The evolution of dignity is described, delineating the main dignity theories in palliative care.

Chapter 3: Literature Review. This chapter presents an integrative literature review that explores and synthesises the evidence on dignity within palliative care in the Middle Eastern context. The review followed the Whittmore & Knafl (2005) integrative method that incorporates quantitative and qualitative papers to develop a comprehensive understanding of the phenomenon. The search strategy, inclusion/ exclusion criteria, data extraction and the seven themes generated from the included papers are presented culminating in seven themes of dignity. The findings are compared for similarity to the Chochinov model of dignity. The review was published as: Dakessian Sailian, S., Salifu, Y., Saad, R., & Preston, N. (2021). Dignity of patients with palliative needs in the Middle East: an integrative review. *BMC Palliative Care*, 20(1), 112. <https://doi.org/10.1186/s12904-021-00791-6>

Chapter 4: Methodology. This chapter presents the philosophical orientation of social constructionism and the rationale for using qualitative methodology and reflexive thematic analysis by Braun and Clark (2006). It describes the data collection method, sampling, recruitment, and data analysis. The chapter also includes a section on the researcher's reflexivity and methods applied to assure the trustworthiness of the research.

Chapter 5: Methods. Here the methods used for conducting the research are described. The sampling method, recruitment, ethical committee approval, and method for interviewing is detailed with their subsequent rationale. The data analysis method by Braun and Clark (2013) is also described with supporting steps on how to maintain the quality of the research.

Chapter 6: Findings from patients' experiences. The demographics of the participants are described. The four themes and sub-themes developed from the patients' interviews that describe their perception of dignity and attributes of dignified health care are elaborated. The four themes are a) the importance of faith, b) the need to preserve physical, social and mental wellbeing c) the central role of family and children, d) compassionate health services. The sub-themes are displayed as a visual thematic map.

Chapter 7: Findings from family caregivers' experiences. The demographics about the family caregivers are described and the four themes and their sub-themes analysed from the family caregiver's data. The themes are a) duty for kind and loving discourse, b) securing a good quality of life, c) maintaining the social role in the society, and d) the role of health services in maintaining dignity. A thematic mapping of the findings is displayed.

Chapter 8: Discussion. This chapter compares the findings between patient and family caregivers' interviews, identifying similarities and differences. It then evaluates the themes against the integrative review conducted (chapter 2) and wider international literature including the Chochinov model of dignity. The findings are distilled and illustrated in a proposed new model of dignity: the 'flower of dignity'. The chapter ends with a personal reflection and implications for practice, policy, and research.

Chapter 2. Background

In this chapter I describe the context of Lebanon, giving an overview of its demographic composition, the fragmented health care system, and the intensifying socio-political turmoil amid Covid-19 pandemic. The chapter gives an exposition of palliative care development, highlighting how preserving dignity of patients is an integral part of palliative care. The infancy of palliative care in Lebanon, common practices and challenges are elaborated. Finally, theories of patient dignity in the palliative care context are outlined, focusing on the Chochinov Model which is chosen as a benchmark for comparison in this thesis.

2.1 The Socio-political State and Health System in Lebanon

Lebanon is a small Arab country on the Eastern coast of the Mediterranean Sea with a population of 6.8 million (WorldAtlas, 2021). It is bordered by the Republic of Syria from the north and east, bounded by state of Israel from the south, and the Mediterranean Sea from the west. Though regarded as an Arab country, its heterogeneous population, multiple spoken languages like Arabic, French, Armenian, and Kurdish, and the rugged geography of mountains, green valleys, and sandy shores in the south differentiates it geographically and socially from the Arab region. The social fabric of Lebanon consists of plural sects and diverse religious ethnic groups striving in the same land (WorldAtlas, 2021). Each of the eighteen officially recorded sects have representation in the governmental parliament that parallels their demographic size in the country (see chart 2.1). The Shia and Sunni are the dominant Muslim groups , while Maronite Christians are

the major denomination among the Lebanese people (CIA World Factbook, 2020; Khalaf et al., 2020).

Lebanon is a democratic country governed by political blocs that enact power and communal autonomy in regional districts. This often creates ideologies and practices within indistinct religious ethnic groups mobilising grounds for privileges in governance (Joseph, 2011). Sectarianism has kept a few influential families in political power for generations who have gained influence, creating a system of informal 'clientelism' that encourages personal service-based relations between citizens and politically influential families or parties, reinforcing the authority of the head of the party 'zaaim' (Joseph, 2011). Political clientelism strengthens loyalty to partisan parties on the account of national or state interests cultivating religious and political divisions and polarisation (Bugh et al., 2021; Harb, 2006; Joseph, 2011). Though Lebanon enjoys a greater level of social openness and tolerance compared to the neighbouring Arab countries, its history is characterised by political unrest, turmoil, and instability influenced by regional conflicts and global political tensions and interests (Calfat, 2018).

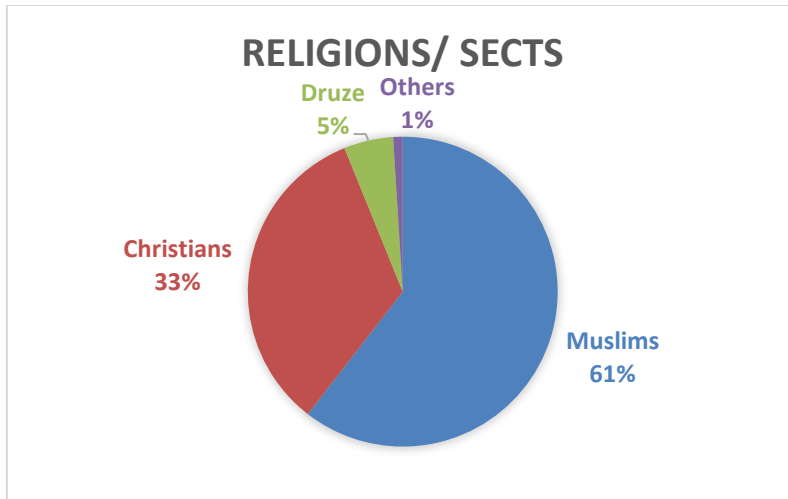


Chart 2.1 Religious demographics in Lebanon

Before the civil war that lasted from 1975-1991, Lebanon was regarded to be a prosperous country, well-known for its banking sector and tourism, repeatedly praised to be the “Switzerland” of the Middle East (Bugh et al., 2021). It enjoyed a booming economy and service sector due to its fair climate, Mediterranean diet, and hospitable culture. When the civil war ended, the government made efforts to refurbish the weak health care system by building hospitals and dispensaries. However, private hospitals took the lead in the health system, becoming the mainstream of medical care, while the public services remained underdeveloped with minimal utilisation (Ammar, 2009).

The services delivered through the privatised hospitals were mainly curative, targeting acute management of medical conditions with an emphasis on advanced, interventional technology (Al-Sudaïd, 2021). Primary health or health promotion services were mostly neglected (Lerberghe et al., 2018). Health services provided by the private sector, though expensive, were perceived to be of higher quality than those delivered by public institutions. The Lebanese Ministry of Public Health reimbursed a long list of surgeries

provided by private hospitals, inpatient and outpatient diagnostic tests, and some essential medicines and this cost coverage often led to over-medicalisation and inflated bills (Lerberghe et al., 2018). Preventive services and primary health care approaches remained fragmented, mostly run by non-governmental organisations and charity groups with no financial subsidisation from the government (Kronfol, 2006). With the weak governance of the ministry, the health care sector was largely commercialised, resulting in reduced access to quality care (Lerberghe et al., 2018). The public hospitals made up only 12% of the total hospitals. Their health services were basic, stigmatised for the poor, and regarded as the last resort for the regular citizen (Kronfol, 2006; Sen & Mehio-Sibai, 2004). Reforms were urgently needed to increase the role of the government from a mere source of funding for private hospitals' services and interventional procedures to an active partner in shaping the nation's health. There was a dire need to regulate the system, set priorities, restore balance between the types of service provision, create equal access and distribution of resources, and uphold quality of practice (Lerberghe et al., 2018; WHO, 2000).

Despite the lack of a national health policy to improve quality (El-Jardali & Fadlallah, 2017), health indicators and outcomes outperformed neighbouring countries (Van Lerberghe et al., 2018). Lebanese private hospitals became a medical hub in the Middle East region catering for many Arab citizens, particularly patients from war- inflicted Iraq, who came to receive cancer or reconstructive therapy. The uninterrupted flow of patients from the Arab region to Lebanon resulted in the country becoming a site for health tourism (Dewachi et al., 2018).

2.2 Government Mismanagement and Triple Crisis

With an unstable political situation, especially with the rise of governmental debts and the increasing polarisation of political parties, the health care success did not last long (Shallal et al., 2021). The economy was compromised with the ongoing war in adjacent Syria since 2011, that led to the influx of more than one million Syrian refugees in 2019, mostly Sunni Muslims, to the existing seven million citizens (UNHCR, 2020). Lebanon was sucked into the vortex of economic downfall as sanctions were applied to Syria (Council of EU, 2021), which transformed Lebanon into a gateway for smuggling goods and essential supplies to the country (Awad & Andre, 2021). The displacement of Syrians strained the Lebanese economy, pressuring its infrastructure, environment, and vital sectors such as the educational and health care system, depleting national resources (UNHCR, 2020; Van Lerberghe et al., 2018).

In October 2019, civil protests were ignited by the austerity measures and high unemployment rates, with protesters demanding social justice and reform (ACLEDA, 2021). These public demands were still unresolved when the first case of Covid-19 was announced in February 2020, increasing economic tension and ushering in a collapse of the socio-political situation. Mistrust in the government was intensified with the massive Beirut Port blast in August 2020 that killed hundreds and injured thousands of civilians. More than two tons of ammonium nitrate stored in the port of Beirut exploded, resulting in the complete destruction of a large area of Beirut downtown and displacing many residents. The explosion left the country traumatised as people lost their neighbourhoods, loved ones, shelter, workplace and livelihoods. The country's vital

institutions were paralysed as large hospitals, schools and industrial institutions were ruined losing total functionality (Devi, 2020; Elghossain et al., 2020).

The country could not endure the triple impact of the massive blast, the raging Covid-19 pandemic, and an economic plunge ensued with the rapid devaluation of the Lebanese pound and exponential hyperinflation in the market (Bugh et al., 2021). With widespread unemployment, more people have suffered from poverty, shortage of food and basic material goods such as electricity and fuel supply. The healthcare system has been adversely impacted with a severe shortage of medical supplies and the emigration of the medical and nursing personnel as salaries collapsed. Lebanese citizens have struggled to receive basic health care and medicines (Human Rights Watch, 2021).

2.3 The State of Palliative Care in Lebanon

In 2014, palliative care was declared as an international human right to be delivered equitably to all who suffered from serious illnesses (Brennan, 2007; WHO, 2014). Palliative care offers the active and holistic care of individuals at the end of life with the aim of improving their own and their families' quality of life (Radbruch et al., 2020). Yet, most patients around the world, particularly in low- and middle-income countries, die in uncomfortable and distressing situations without access to palliation (Abu-Odah et al., 2020; Knaul et al., 2018; Sleeman et al., 2019) Patients' end of life and death is often completely medicalised with little attention paid to individual dignity or communication with the families, and few opportunities for a natural and peaceful ending (Sallnow et al., 2022). Dignity related distress is a concern, as patients with advanced or terminal conditions experience a heightened level of physical, psychological burden (Chochinov

2002 b). Losing dignity is related to being a burden to others, loss of control and autonomy, or worsened physical functionality (Chochinov, 2006; Kennedy, 2016; Oosterveld-Vlug et al., 2013) Dignity is jeopardised when patients' personal lives are violated by illness and they lose meaning and hope in life, often feeling alienated from their environment (Staats et al., 2020). Dignity at the end of life is a central tenet to palliative care.

Palliative care in Lebanon is underdeveloped, echoing the situation found in many of the low- and middle-income countries palliative care. Lebanon is categorised by Lynch et al (2013) as a group 3a country, defined as where palliative care service delivery is isolated, heavily dependent on donors and only marginally supported, with minimal availability of morphine (Lynch et al., 2013). In Lebanon, there are very few home-based palliative care services with only six teaching-hospitals that cater for palliative care needs from a total of 167 hospitals (Daher, 2021; WHO, 2000). Less than fifteen physicians are registered in the Ministry of Public Health as palliative care specialists in a country where the rate of physician is two per 1000 citizen (Daher, 2021; World Bank, 2018). Though the palliative care movement started to take root from 1995, enhanced through the establishment of a National Committee for Pain and Palliative Care in 2012, it has progressed slowly facing multiple impediments in policy, culture, perception, and shortages of resources (Hajjar, 2021; Soueidan et al., 2018).

The mainstream medical practice is to continue aggressive treatment until the end of life, and only where available refer to palliative care services at the point when interventions are exhausted, and a patient is imminently dying (Hajjar, 2021; Mouhaweij et al., 2017;

Rida & Zeineldine, 2013). It is not uncommon to witness patients dying in hospitals while undergoing sophisticated treatments with the justification of prolonging life even if that brings greater suffering (Daher, 2010; Mouhaweij et al., 2017). Heroic attempts at resuscitation by the medical team have gained preference instead of acknowledging when it is more appropriate to allow a traditional or natural death (Ammar & Hamra, 2013). Comfort in care is rarely discussed and is only resorted to when hope for cure is null and a consensus is reached among the primary physician, the patient or his/her surrogate and the head of the concerned medical department to commence a palliative care approach (Rida & Zeineldine, 2013; Soueidan et al, 2018). The prevalent religious belief is that life is a sacred gift from God and illness happens only through God's will. God can provide a cure in times of illness. Thus, maintaining life at all costs is a divine responsibility even if it involves pain and distress (Aramesh & Shadi, 2007; Choong, 2015).

On the other hand, palliative care services are a privilege for the few, as health insurance schemes rarely fund the cost of palliative care services (Soueidan et al., 2018). Some initiatives for pain and symptom management services have emerged as the annual quota for morphine in the country increased from 0.5kg in 1995 to 4.5kg in 2001 (Daher et al., 2002). The Ministry of Public Health provides opioids for individuals who present a medical prescription and a certificate describing the diagnosis. Cancer patients are allowed a one-month supply of the prescribed opioid from pre-specified pharmacies that can be renewed on a yearly basis (Daher & Doumit, 2017). However, overall consumption of opioids remains extremely low compared to Western nations (Duthey & Scholten, 2014).

Communication about advance directives is the least established in Middle Eastern countries (Silbermann et al., 2015). Most patients at the end of life are unaware of their rights to assign a proxy to voice their preferences if they were to be incapable of doing it due to the illness (Feghali et al., 2018). Documenting patient wishes or preparing advance directives are not endorsed by law (Rida & Zeineldine, 2013). Anticipatory planning for end of life is not addressed as total disclosure of a patient's prognosis is not regularly practiced due to hesitancy in sharing information from families and physicians (Bou Khalil, 2013; Feghali et al., 2018). Though the Lebanese decree recommends physicians to reveal the nature of illnesses or possibility of imminent death to the patient, it also allows the physician to refrain from revealing a poor diagnosis based upon personal/professional preference and judgement (Code of Medical Ethics, 2012). Farhat et al. (2015) reported that 83 % of physicians were in favour of disclosure, however, only 14 % communicated the diagnosis to their patients. Physicians also have the habit of using alternative terminologies such as 'severe inflammation' or 'intravenous medication' evading the word cancer or chemotherapy while communicating with their patients (Feghali et al., 2019). Since families play a key role and hold a heavy responsibility in patient care, physicians often reveal the truth to one of the family members who may in turn conceal it from the patient (Khalil, 2012; Osman, 2015). Excluding the patient from the end-of-life discussions is practised with the intent of protecting the patient from psychological despair, particularly in patients with cancer, due to the attached stigma and perceived incurable nature (Osman, 2015). Often, close family members are uncomfortable in acknowledging the probability of death, supporting futile interventions with false expectations of

recovery (Silbermann et al., 2012). Such situations and dynamics usually lead to over-treatment and high frequency of hospitalisations (Osman, 2015).

2.3.1 The Effect of Covid-19 Pandemic on Palliative Care in Lebanon

During the Covid-19 pandemic, only two hospitals with palliative care services provided support to their patients through telephone calls with the intention of keeping patients at home (Yamout et al., 2020). Health care providers tried to separate patients with cancer in dedicated departments distancing them from patients with Covid-19 infection. The Lebanese society of medical oncology recommended that physicians discuss the benefits and risks of therapies and accordingly limit or delay weekly curative therapy to patients with metastatic disease or poor prognosis to accommodate the high influx of patients infected with Covid-19 (Bitar et al., 2020). However, it is unclear whether this recommendation was implemented or resulted in effective management of cancer patients as some were reluctant to modify the treatment plan (Kattan et al., 2020). Though the provision of palliative care during a pandemic is an essential part of comprehensive response to the high rates of death and hospitalisations (The Lancet, 2020), there has been no national attempt to reactivate the role of palliative care teams. Hospitals were overwhelmed and ran short of nurses, critical care beds and medical supplies as a result of both the pandemic and the economic recession. It has been forecasted that the impact of Covid-19 could have severe implications in limiting medical supplies and health resource in poor countries (Salifu, et al., 2020). Patients assigned to curative treatment were prioritised over those with palliative needs, who were advised to stay home and receive support through telemedicine when feasible (Kattan et al., 2020).

The need for palliative care is more pressing in Lebanon than ever as non-communicable diseases and the ageing population are rising (Abdulrahim et al., 2015). Studies showed that around 15,000 patients need palliative services on a yearly basis (Soueidan et al., 2018). As mortality rates have increased due to the Covid-19 pandemic (Knoema, 2020) Lebanon is expected to have a higher need for palliative care to address health related suffering. However, most patients perceive modern medical treatments superior to any other alternative therapy and prefer doctors who have mastered the state-of-the-art medical technology (Ayoub et al., 2015). The patient-physician relationship is non-egalitarian with physicians or family relatives as the dominant decision makers for the patient's care (Ayoub et al., 2015). Some patients perceive that the relationship is flawed by the physician's intention of making a profit from the patient's illness rather than caring for the patient (Arawi, 2010). Though the Lebanese data is scarce and insufficient to generalise, it seems that the social, political, and medical grounds are still not ready for embracing integrated palliative care services.

2.4 Evolution of the Concept of Dignity

The concept of human dignity has received wide attention over the centuries in human sciences, social discourse, human rights, and clinical practice (United Nations, 1948; Willison, 2016). The recent movement 'Black Lives Matter' in 2020, reveals a call for social justice and equality with the urgent need to protect human dignity with no racial discrimination (Bhattar, 2021). The state of human dignity has been argued by scholars, historians, and theologians and its definition analysed from Aristotle to Cicero, Hobbs, Rousseau, Kant, and others (Sychev, 2017). According to a Kantian approach, a German

philosopher in the 18th century, dignity is an intrinsic value grounded in all individuals who have moral autonomy and agency to do good. Dignity is rooted in human acts of morality and righteous behaviour placing humankind above all other living things (Kant, 1981). Dignity has also been ascribed to social status, rank, prestige, and position acquired with hierarchical understanding amongst others in society. In this social and relational understanding, people of higher office such as an archbishop or a duke are warranted higher worth, respect and virtue (Cicero, 1991; Waldron, 2009).

In the last century, the concept of dignity has been transformed into a universal feature that underlines the central framework of human rights as freedom, justice, and peace. The concept has evolved as a foundation of constitutions and organisations, and a key element in creating democratic states (Stein Messetti & de Abreu Dallari, 2018). The United Nations in advancing human rights, declared legislation on *patients' rights* to access health and medical care, information, privacy, non-discriminatory and quality care (Beletsky et al., 2013) . Health services offered to patients were increasingly required to comply with human rights norms and agreements, chartered in different international or regional treaties, in order to provide a safe environment to receive and deliver health services to all agents, patients, and providers (ECHR, 2013; ESC, 2015). Human rights laws create a foundation to deter violations of human dignity such as breaching confidentiality, denying pain relief, imposing treatment on patients, and so forth. The right to human dignity incorporates a patient's freedom 'to control health and body', the right to respect private and family life, the right to information, and the right to accessibility of health services without discrimination, as integral components of health care to promote human

wellbeing and a fair society (Cohen & Ezer, 2013). The UK Human Rights Act 1998, for instance, ensures human rights for patients are respected and protected by public or private health bodies, where rectifying action is introduced when violations occur (Whitehouse, 2020).

2.5 Dignity in Illness and in Palliative Care

Affirming human dignity is recognised in several international initiatives. For example, the Europe wide Amsterdam Declaration on Promoting Patients' Rights calls for patients to be treated with respect and integrity in health care (WHO, 1994). Dignity is a well-established tenet in the International Council of Nurses (2021) code of ethics, which states that all patients have the right to life, the right to choose and the right to be treated with dignity without discrimination in age, gender, colour, religion, ethnicity, sexual orientation, socioeconomic status, or other affiliations (International Council of Nurses, 2021).

Patients with advanced chronic or terminal illnesses such as cancer or organ failure may experience an array of physiological, psychosocial, spiritual, and existential challenges that reduce their sense of worth or purpose in life. They can experience a loss of dignity and a diminished desire to live (Chochinov et al., 2006, 2016). Heightened functional dependency in serious illnesses, loss of hope, control and autonomy can negatively impact self-image, leading to isolation and declined quality of life (Chochinov et al., 2002; Enes, 2003).

In acute care hospital settings, patients have identified poor health status and loss of personal privacy as threatening to dignity (Tehrani et al., 2018). Health care providers' attitudes and approaches toward the patient, such as an authoritarian or curt

communication adversely impacts a patient's dignity (Baillie, 2009; Tehrani et al., 2018). (Baillie, 2009; Tehrani et al., 2018). In intensive care units, shared human values between health care providers and patients, respecting personal stories and patient autonomy endorses the commitment to uphold patient dignity amid severe illness (Henry et al., 2015). For patients facing incurable illnesses and living at home, dignity has been found to include feeling treasured, able to make your own decisions, and feeling hope and meaning in life. Feeling dignified was more affected by the approach of carers to patients during the time of illness than the place patients resided (Staats et al., 2020).

Bodily changes due to the illnesses or treatments can bring forth feelings of shame and vulnerability that may threaten patient dignity, particularly when relying on others for self-care, services, or planning of care (Bagheri, 2012; Kennedy, 2016; Lorentsen et al., 2019). Dignity of an individual is not only endangered by the physical changes caused by the illness but also through social positioning and patient experiences when seeking essential health services (Chochinov, 2007). Urgent needs when sick, including the vulnerabilities of being poor, ashamed, or having asymmetry or inequality in relationships, are all in a dynamic interplay affecting the perception of dignity or its violation (Jacobson, 2009). In the wider understanding of patient dignity in the health care setting Jacobson, (2009b), explains how discrimination, exclusion, objectification, and deprivation are some of the acts that violate dignity.

A sense of dignity in institutionalised older adults in need of palliative care is influenced by the health care facility, staff members' attitude and behaviour, patient's independence, and personhood in relation to family, friends, and society (Hasegawa & Ota, 2019; Lin et

al., 2012). In older adults, human dignity is conceptualised as maintaining identity, integrity and the ability to have free choice associated with control and self-determination (Woolhead et al., 2004). Professional attendance for optimum medical aspects of care should include a holistic caring for a patient that emphasises a holistic attention and validation of the unique stories and concerns that accompany the individual during the illness (Paulson, 2004).

Patients in Iran were found to experience dignity when medical resources and facilities are accessible, and treatment is delivered by same gender health care providers. Impersonal communication, infringement of personal privacy by health care staff is perceived to damage dignity (Ebrahimi et al., 2012). Evidence has revealed that 7.5 % of terminally ill cancer patients in palliative care units in Canada, have concerns about the loss of their dignity. These patients had relatively higher psychological distress, symptom burden and greater dependency that led to a loss of vitality to continue life (Chochinov et al., 2002b). Non-cancer patients also experience mild to moderate levels of loss of dignity due to varying levels of distress and unique difficulties at the physical, psychological, or spiritual dimension at end of life (Chochinov et al., 2016).

Though dignity is a universal human need, it is complex, cultural, entailing multiple dimensions (Kennedy, 2016). Its conceptualisation is influenced through the context carrying different connotations and implications in health care provision (Lou et al., 2020). The perception of dignity during illness is affected by the social agency of the actors, the overall properties of the setting, and the prevailing societal order that affects social interactions, interpretations, and patterns of behaviour within and among individuals

(Jacobson, 2009). Language, religion, social frameworks, economic stability, the health care system, and context of time and place are in an active interplay shaping patient needs and experiences of illness and dignity (Cottrell & Duggleby, 2016; S. Dakessian Sillian et al., 2021; Lou et al., 2020; Van Gennip et al., 2013). In Lebanon, whilst protecting patient dignity is not explicitly stated in the Lebanese patients' rights laws (MOPH, 2004), it is part of the Lebanese medical ethics (Code of Medical Ethics, 2012). However, as yet no study exists to shed light on the experience of dignity of patients in Lebanon.

2.6 Theories about Dignity

Several theories about dignity have been developed in the context of palliative care.

Dignity in hospitalised patients with advanced cancer was explored by Chochinov et.al, (2002) in Canada through a qualitative study, who established a model of dignity that composed of three categories: *Illness related concerns, dignity conserving repertoire, and social dignity inventory*. Each domain was elaborated with themes and subsequent sub-themes (see figure 2.1). The first category; *illness related concerns*, explained how the consequences of the illness, such as decline in cognitive ability, functional dependence, and heavy symptom distress, affect dignity. The second category; *dignity conserving repertoire* was related to the attitudes, or the practices adopted by the patient to continue life and enhance dignity despite the illness. Measures such as preserving social role, accepting change, leaving a legacy to the family, seeing self as valued, hopefulness, maintaining normalcy, living the moment, and seeking spiritual support were all delineated as behaviours the patient sought to ease the situation. *The social dignity inventory*, the third category, articulated the effect of relationships and environment upon

patient dignity. This was elaborated by the amount of social support the patient receives, care tenor, feeling a burden on other, the aftermath concerns and preservation of personal boundaries.

The 'ABCD's guideline (Attitude, Behaviour, Compassion, Dialogue) of dignity-conserving care was devised to assist clinicians about being mindful of pre-assumptions, respecting human uniqueness, and maintaining kindness and compassionate dialogue as core values in supporting patient dignity and wellbeing (Chochinov, 2007).

Based on the Chochinov Dignity Model, several dignity assessment tools such as the Patient Dignity Question (PDQ) & Patient Dignity Inventory (PDI), (Chochinov et al., 2008) as well as a psychotherapy for conserving patient dignity (Dignity Therapy) in palliative care were developed to mitigate distress in people at the end of life (Chochinov et al., 2011). The Patient Dignity Question (PDQ) "What do I need to know about you as a person to take the best care of you that I can?" derived from the model of dignity is used to improve person-centered care and conserve dignity in patients with palliative needs. When health care providers ask the question it leaves a positive impact on patients' perceptions of care and of health providers' attitudes showing keen desire to know more about what matters to the person behind the patient with palliative care needs (Johnston et al., 2015).

A psychotherapeutic intervention, 'Dignity Therapy', addressed the psychological and existential concerns of patients at the end of life, allowing them to reflect and record their important life events and grant it as a legacy to their loved ones (Chochinov et al., 2005).

Through this intervention many patients affirmed their uniqueness and their value as a human being bringing forth an increased sense of meaning and purpose in life alleviating dignity related distress (Cuevas et al., 2021; Martínez et al., 2017). Dignity therapy had high acceptability and feasibility from patients with a terminal illness (Beck et al., 2019; Bernat et al., 2015), and also provided comfort to family caregivers during bereavement decreasing anxiety and depression (Bentley et al., 2012; Cuevas et al., 2021). Dignity therapy was more convenient when conducted in the home setting but sometimes needed modifications to have cultural congruence with non-western conceptualisations of dignity (Li et al., 2014).

Furthermore, the Dignity Conserving Intervention (DCI), a nursing care pathway that emanated from the Dignity Model, was applied by community nurses in Scotland to patients at the end of life. The DCI facilitated holistic assessment of the patient, opening the space to identify and address various dignity related concerns (Johnston et al., 2017; McIlfatrick et al., 2017).

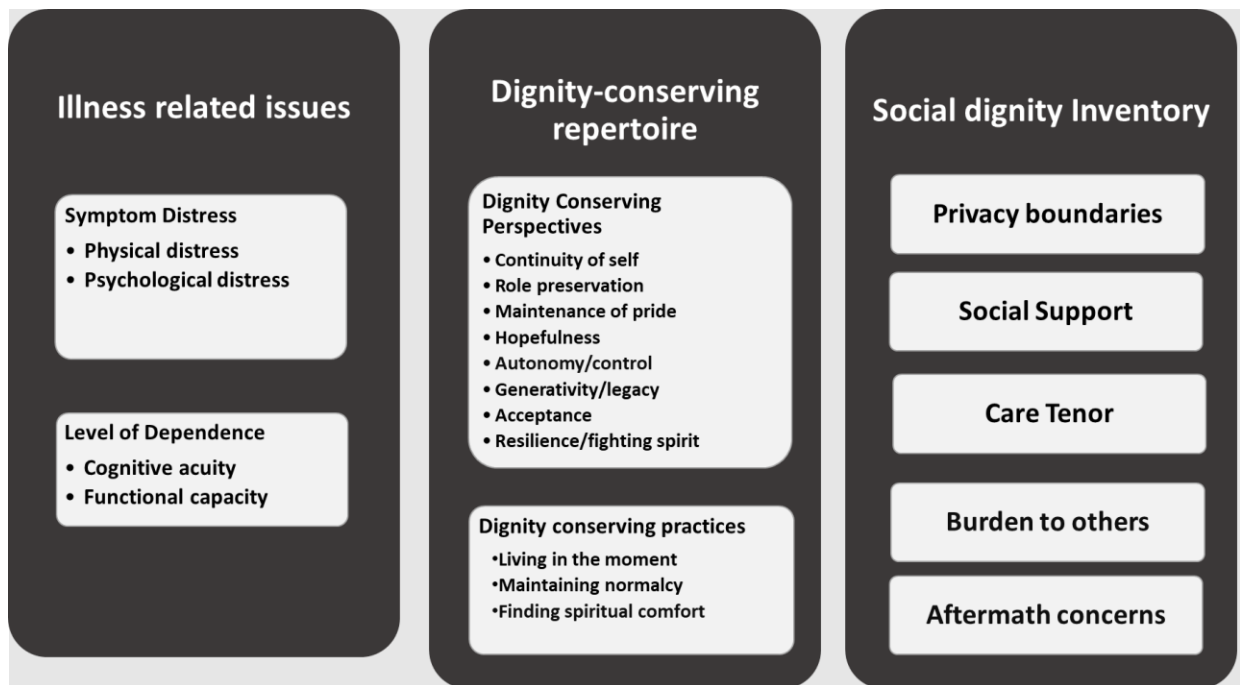


Figure 2. 1 The adapted Dignity Model by Chochinov (Chochinov et al, 2002)

The Chochinov model has been (Chochinov et al., 2006; Hack et al., 2004) widely employed in palliative care and end of life research in different parts of the world from Iran to China (Bagheri et al., 2018; Hall et al., 2009). Though the three categories of the Chochinov Model are broadly supported in different parts of the world, cultural deviations such as the familial duty to take care of the ill families (Lou et al., 2020), or resignation to God's will to establish a sense of peace (Le et al., 2014; Ho et al., 2013) have appeared to surface as important themes that reveal how context, socio-cultural diversities and religious milieus impact the perception and restoration of dignity in palliative care patients (Kadivar et al., 2018).

Other dignity models have been developed such as the 'Model of Dignity in Illness' by Van Gennip et al. (2013) . This was developed from interviews with a wider population experiencing serious illness such as cancer, dementia, Human Immunodeficiency Virus (HIV), or Crohn's disease. This model explains dignity as a concept affected by the

- a) Subjective experiences and personal reflection of the individual
- b) The relationships of the patient with others and how illness affects personal value and significance.
- c) The general societal responses to their illness.

This model presented dignity in its three dimensions, that of the self, relational and societal (Van Gennip et al., 2013).

Dignity was also portrayed as being personal and socially constructed concept through relationships in the work by Pleschberger (2007) on older adults in German nursing homes. Her 'Dignity Conceptual Model' recognises that illness places the individual in the position of needing various types of care such as social, physical, and financial. The vulnerable situation of frailty and ill health threatens the dignity of nursing home residents fostering a perception of being a 'burden' to others. The several losses experienced by older residents, be it a partner, friend, home, possessions, career, and functionality weaken their sense of dignity (Hall et al., 2009).

A framework of 'Dignity- Driven Decision Making' was developed to promote collaborative decision making with people with advanced illnesses in the US (Vladeck & Westphal,

2012). This framework worked on applying a comprehensive plan to determine the goals of care, implementing it through continuous collaboration between the patient, the family, and the clinician.

Jacobson (2009b) created a taxonomy and framework of the concept of dignity in the wider context of health and human rights. The model produced two forms of dignity: human and social. The human form pertains to the humaneness of the individual, which is universal and enduring, while social dignity is affected through encounters that may promote or violate dignity. Dignity is affected by the social position of the individual, the features of the relationships and how the person is treated by others and the effect of the overall social order. When the relationship is asymmetrical between two individuals in terms of knowledge, strength, health, wealth or power it situates the weak to a vulnerable situation where dignity can be violated. A harsh environment that is characterised by a rigid, hierarchical setting characterised by stress, urgency and lack of resources does not promote dignity. The framework proposes that dignity is cultivated when there is social justice and equality that provides access to health, education, social services and basic needs such as housing (Jacobson, 2009b).

Though all the conceptualisations of dignity of patients in palliative care give useful insight into patient needs, the Chochinov Model was recognised to be the most dominantly utilised in palliative research and hence the lens through which this research was viewed.

2.7 Conclusion

Maintaining patient dignity is a central value in palliative care. Dignity in palliative and end of life context has been studied in Western countries but not in Lebanon. Palliative care is

not a common practice in the Lebanese health care system because curative treatment is the mainstream. Consequently, the research aimed to answer the following question ‘How is dignity interpreted and maintained by patients with palliative care needs and family caregivers in the Lebanese context’ that is timely to explore dignity conceptualization from a Middle Eastern perspective. To achieve this understanding, the study had four objectives:

- A) Explore the interpretations of the concept of dignity in adult patients with palliative needs as perceived by patients and family caregivers.
- B) Examine how dignity is experienced while receiving health services in patients with palliative needs from patients’ and family caregivers’ perspective.
- C) Assess how family caregivers perceive and preserve the dignity of their relatives with palliative needs during illness and while receiving health care services.

Critically assess and compare the findings of the research on dignity in relation to the Chochinov’s Dignity Model. In the next chapter, the concept of dignity is explored through the integrative literature review that synthesised the knowledge and understanding of dignity in palliative care within the Middle Eastern context.

Chapter 3. How is Dignity Understood and Maintained in Patients with Palliative Needs in the Middle East? An Integrative Review

3.1 Introduction

Various barriers prevent the integration of palliative care in health services in Middle Eastern countries. These barriers are related to community awareness, scarcity of resources to provide palliative care in relation to trained staff, time, and essential medicine like opioids (Silbermann et al., 2015). The availability and access to opioids to alleviate the pain of patients with terminal or advanced illnesses is restricted through local legislation in fear of addiction. Many patients with advanced cancer are treated with non-opioids such as non-steroidal anti-inflammatory agents (Fadhil et al., 2017).

Palliative care education in the Eastern Mediterranean area is not fully incorporated into medical and nursing educational curricula, leading to inadequate well-trained palliative care specialists consequently limiting the access to quality palliative care (Fadhil et al., 2017; Kolmar et al., 2019; Osman et al., 2017).

The integration of palliative care in the national health plan and its acknowledgment as a separate discipline is limited, rendering palliative care services fragmented and funding scarce (Osman et al., 2017). The absence of national laws regulating advance decisions such as “do not resuscitate” orders, and barriers to communicating poor prognosis, presents a hindrance to the development and provision of palliative care, advance care planning and consequently exploring and endorsing patient preferences (Fearon et al., 2019; Kolmar et al., 2019).

Often the unstable geopolitical, economic, and the mosaic sociocultural fabric of the region that is under a strong influence of religion, traditions, and culture, shapes the understanding and maintenance of human dignity in palliative care settings impacting community responses, clinical practice and policy development (Fearon et al., 2019; D. Schroeder & B. Bani-Sadr, 2017; Silbermann et al., 2012).

Since the family unit, religion, reliance on God, are recurrent values that envelope the Middle Eastern Arab individual (Aljawi & Harford, 2012; Fearon et al., 2019; Gustafson & Lazenby, 2019), the concept of patient dignity needs exploring including its nuances in comparison to other contexts, particularly to the dominant Western understanding. Upholding patient dignity is not only a key principle of palliative care but a core ethical value in nursing (International Council of Nurses, 2021) as well as medical practice (The World Medical Association, 2018). Greater understanding of this phenomenon in the Middle East would inform health care providers, informal caregivers, and educators to attend to and protect the dignity related needs of palliative care patients with cultural humility and competence. No published systematic review has been found that addresses the concept of dignity in palliative care in the Middle East. Hence an integrative review was undertaken to explore this which was published in 2021 (Dakessian Sallian et al., 2021).

3.2 The Review Question and Aim

What is the understanding of dignity, and how is dignity preserved in patients with palliative care needs in the Middle East?

The overarching aim of this review is to explore, appraise and critically synthesise the evidence on the concept of dignity in the Middle Eastern palliative care setting from the perspective of the patients, health care providers, and family caregivers, examining how dignity is enhanced or undermined while receiving care. This review looks at:

1. The perceptions of the concept of dignity from the perspective of the patient, family caregiver, or health care provider within adult palliative care in the Middle Eastern region.
2. Behaviours of health providers or aspects of care that enhance or undermine the sense of dignity in patients with palliative care needs during illness and while receiving health services.
3. Critically assess the findings against the Chochinov Dignity Model which is dominant in the Western literature.

3.3 Review Method

An integrative method was adopted for this review (Whittemore & Knaf, 2005). An integrative review combines studies with diverse methodologies conveying a better understanding of complex phenomena. The inclusiveness of various research designs facilitates the building of comprehensive evidence useful to guide clinical practice and policy. This openness to diverse methodologies allows a clear definition of concepts, appraisal of the existing evidence, and identification of knowledge gaps (Whittemore & Knaf, 2005). To enhance rigour, a systematic and explicit methodology is applied throughout the review process, informed by the guidelines set by Whittemore and Knaf (2005) as follows:

1. Problem identification
2. Literature search
3. Data evaluation
4. Data analysis
5. Conclusion
6. Verification

3.3.1 Problem Identification

The problem identified in this review is exploring the understanding of the concept of dignity in patients with palliative care needs in the Middle Eastern region. To the researcher’s knowledge there is no review to answer this question.

3.3.2 Literature Search

The SPICE (Setting, Perspective, Intervention/ Phenomenon of Interest, Comparison, Evaluation) search framework, that is appropriate for explorative questions, is applied to the research question to separate into elements, expand search terms, and specify study eligibility criteria for inclusion (Booth et al., 2016). The SPICE framework was selected because it clearly specified the Setting, the Perspective, and the Phenomenon of Interest which were the main elements of the review question. The elements of the SPICE are elaborated in Table 3.1.

Table 3. 1 SPICE Framework

Setting	Palliative care in Middle Eastern countries
Perspective	Adult patients, health care providers, family caregivers, or any other member in the palliative care team.
Intervention/ Phenomenon of Interest	Studies that focus on the phenomenon of dignity.
Comparison	Having impaired dignity
Evaluation /outcomes	The perceived outcome of dignity or loss of dignity.

Definition of key terms:

- Dignity: “the quality or state of being worthy, honoured, or esteemed” (Merriam-Webster online, 2018).
- “Patient with palliative care needs”: is the individual suffering from a life-threatening condition that holds no possibilities of remission or cure. This encompasses patients suffering from a diverse incurable or progressive long-term illnesses such as cancer, organ failure, or degenerative diseases, who require physical, psychosocial, and spiritual care (Van Mechelen et al., 2012).
- Middle-Eastern countries sometimes termed as Eastern Mediterranean countries including the following 18 countries: Afghanistan, Bahrain, Cyprus, Egypt, Israel, Iran, Iraq, Jordan, Kuwait, Lebanon, Oman, Palestine, Qatar, Saudi Arabia, Syria, Turkey, United Arab Emirates, and Yemen (World Atlas, 2016).

3.3.3 The search strategy

A preliminary scoping search was undertaken to be familiarised with the common terms associated with the term ‘dignity’. After consulting with a health librarian, a comprehensive search strategy was designed and applied to four health databases: EMBASE, PsycINFO, PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL). These databases are reported to retrieve a broad range of literature on palliative care (Tieman et al., 2009) and are often chosen in other palliative care reviews (Guo & Jacelon, 2014). Keywords, medical subject headings (MeSH) and multiple synonyms such as, "dignity", "respect", "self-concept", "self-esteem", "palliative care", "terminally ill patients", "life-threatening", "end of life", "dying", "Arab", "Muslim", and

"Mediterranean" were used simultaneously to search the titles and abstracts of captured papers. See Table 3.2

Table 3.2 Search terms and strategy used in CINAHL database, keywords, and Mesh.

Subject group	Search terms used
Dignity	TI ((Dignity OR dignified OR respect* OR person#hood OR "self-concept" OR "self-esteem" OR Distress* OR ((attitude OR good) N2 (death OR dying OR illness))) OR
	(MM "Human Dignity") OR (MM "Respect") OR (MM "Self-Concept")
AND	
Palliative	TI (((palliat* OR terminal* OR hospice OR dying OR death) N2 (patient* OR experience* OR care OR phase OR prognosis OR ill* OR cancer)) OR " end of life" OR end-stage OR life threatening OR life limiting OR (final OR last) N2 (day*) OR " advanced cancer" OR
	(MM "Palliative Care") OR (MM "Terminal Care") OR (MM "Hospice Care") OR (MM "Terminally Ill Patients") OR (MM "Death")
AND	
Middle East countries	TI ((Cypr* OR Afghanistan* OR Bahrain* OR Iran* OR Iraq* OR Israel* or gaza OR ghazza# OR "west bank" OR Palestin* OR Jordan* OR Leban* OR Liban OR Syria* OR Oman* OR Qatar* OR Kuwait* OR Saudi* OR " Saudi Arabia" or Turk* OR UAE or "united Arab emirates" OR Egypt* OR Yemen* OR Mediterranean OR Muslim* OR Islam* OR oriental OR Arab* OR middle#east OR ((cultur* or multicultur*) N2 (divers* OR chang*)))
	(MM "Culture") OR (MM "Cultural Diversity") OR (MM "Middle East") OR (MM "Islam") OR (MM "Arabs")

The search was conducted in December 2020. No date limits were set. The search strategy was modified on each database to adapt to its subject index or thesaurus terms (Sindhu &

Dickson, 1997). The controlled vocabulary and free terms of each concept are combined in the search using the Boolean operator "OR". Once each concept is combed, the searches were united with the Boolean operator "AND" to distil the final number of papers intersecting the three concepts. Supplemental methods of screening were employed to enhance the sensitivity of the search such as scanning the reference lists and forward citation tracking of review papers and included manuscripts, and hand searching of key journals (Booth et al., 2016). The online journals which were hand searched were, 1) Nursing Ethics, 2) The Medical Journal of Ethics, 3) Journal of Medical Ethics and History of Medicine that publish relevant papers on dignity and were screened for the last ten years (2010-2020). The retrieved manuscripts were vetted against the inclusion/exclusion criteria elucidated in Table 3.3. A sample of search syntax and the generated hits from CINAHL database are available in Appendix A.

3.3.4 Inclusion-Exclusion Criteria

The following criteria were followed for selecting the studies (Table 3.3).

Table 3. 3 Summary table of Inclusion and exclusion criteria

Framework	Inclusion	Exclusion	Rationale
Setting	<p>A middle Eastern context</p> <p>The setting is that of palliative care inclusive of hospital, hospice, home-based, or community.</p>	<p>The countries of Algeria, The Comoros Islands, Djibouti, Mauritania, Morocco, Somalia, Sudan, Libya, Pakistan and Tunisia, though considered to be part of the Eastern Mediterranean region, are excluded from the search.</p>	<p>They are geographically distant from the Middle- Eastern and considered to be north Africa.</p>
Perspective/ participants	<p>Studies from the perspective of:</p> <p>a) Adult patients with life-threatening or advanced chronic illnesses such as cancer, or any organ failure (heart, kidney, liver pulmonary), and neurological disorders, who need palliative care attention.</p> <p>b) Health care providers like physicians, nurses, social workers, pharmacists, psychologists, dietitians, and chaplains</p> <p>c) Caregiver- or ‘carer’ described as an adult, aged 18 or over, who provides or intends to provide care for another adult needing care. It could be a family member, relative or other. This excludes people providing paid care or people providing care as voluntary</p>	<p>Older adults or frailty or patients with dementia.</p> <p>Patients with mental health disorders.</p> <p>Paediatric population</p>	<p>Dignity in dementia or frailty entails addressing unique care needs especially in the advanced stages (Holmerova et al., 2007).</p> <p>Many mental health patients suffer from marginalisation and injustice implying a broader action on dignity than that of palliative patients (Saxena & Hanna, 2015).</p> <p>Children within palliative care have unique dignity needs that differ from adults (Muckaden et al., 2011).</p>

	<p>work (National Institute For Health & Care Excellence, 2017).</p> <p>Studies limited to adult population – age >18 years</p>		
<p>Intervention/ phenomenon of Interest</p>	<p>Studies that focus on dignity, the meaning or perceptions of dignity, dignity experiences, dignity related distress, loss of dignity, and dignified care.</p> <p>Studies related to barriers or enhancers of patient dignity will be included.</p> <p>Only empirical studies from peer-reviewed journals that follow quantitative, qualitative, or mixed-method design are included.</p> <p>Only English language papers were included.</p>	<p>Dignity discussed in relation to euthanasia, assisted suicide, assisted dying, right to die, death with dignity, or legislative aspects.</p> <p>Review articles, reports, editorials, commentaries, letters to the editor, books, dissertations, and papers that discuss dignity from legal or policy perspectives are excluded</p>	<p>Dignity is the key focus of the review</p> <p>Palliative care is understood as an approach that affirms life and does not hasten or postpone death. Its role is not only during the last days of life but from the time of diagnosis of an incurable disease. The goal is to improve the quality of life of those facing terminal illnesses as well as their family caregivers. For this reason, papers that tackle assisted suicide or euthanasia are outside the scope of the review and will be excluded (World Health Organization, 2017).</p> <p>Empirical studies are deemed appropriate to provide evidence on</p>

			<p>perceptions, influencing factors, or outcomes of dignity.</p> <p>Due to restricted resources, papers are limited to English language.</p>
Evaluation/ Outcomes	<p>The outcome of enhanced or impaired dignity as well as perceived benefits or threats will be examined. Studies that have dignity as a secondary outcome will also be included.</p>	Outcomes other than dignity	

3.3.5 Search Outcomes & Data Extraction

The search identified 5007 records from the four health databases, and then were transferred to EndnoteX8 bibliography software for filing and removing duplicates.

Seventy-three additional relevant papers were identified from hand searching the three journals and 33 from citation tracking of reference lists of review and included papers.

After eliminating duplicates (n=2625), 2488 papers were screened independently by two researchers (S.D.S.) and (R.S) by title and abstract against the inclusion criteria. The papers (n=2194) that did not meet inclusion criteria were excluded. The potentially relevant papers (n= 294) were filed in Endnote for full manuscript review. A further 266 papers were excluded because they were not directly related to the concept of dignity. Finally, 28 potentially relevant papers remained for a full script reading and data extraction.

In line with the Whitemore and Knafl (2005) guidance, the data from the 28 papers were reduced and displayed in an excel sheet in the form of a table. The table delineated the main characteristics of each paper such as the author, date of publication, country of origin, discipline, study design, aim, participants, context, sample size, data collection, data analysis, and findings. In the findings column data was extracted and specific details that addressed the research question was recorded. Actual quotations from the primary papers were incorporated, too to preserve their uniqueness. The tabular display allowed the visualisation and the iterative examining of the papers to identify their distinctive characteristics. A second reviewer (R.S.) independently extracted the data from 50% of the included papers to validate the process of extraction and relevance of the records. After discussion and consensus with the wider team (NP, YS and RS), 16 dignity papers

were included for final synthesis as a closer examination the remaining 12 papers did not meet the inclusion criteria. The PRISMA chart in Figure 3.1 displays the process.

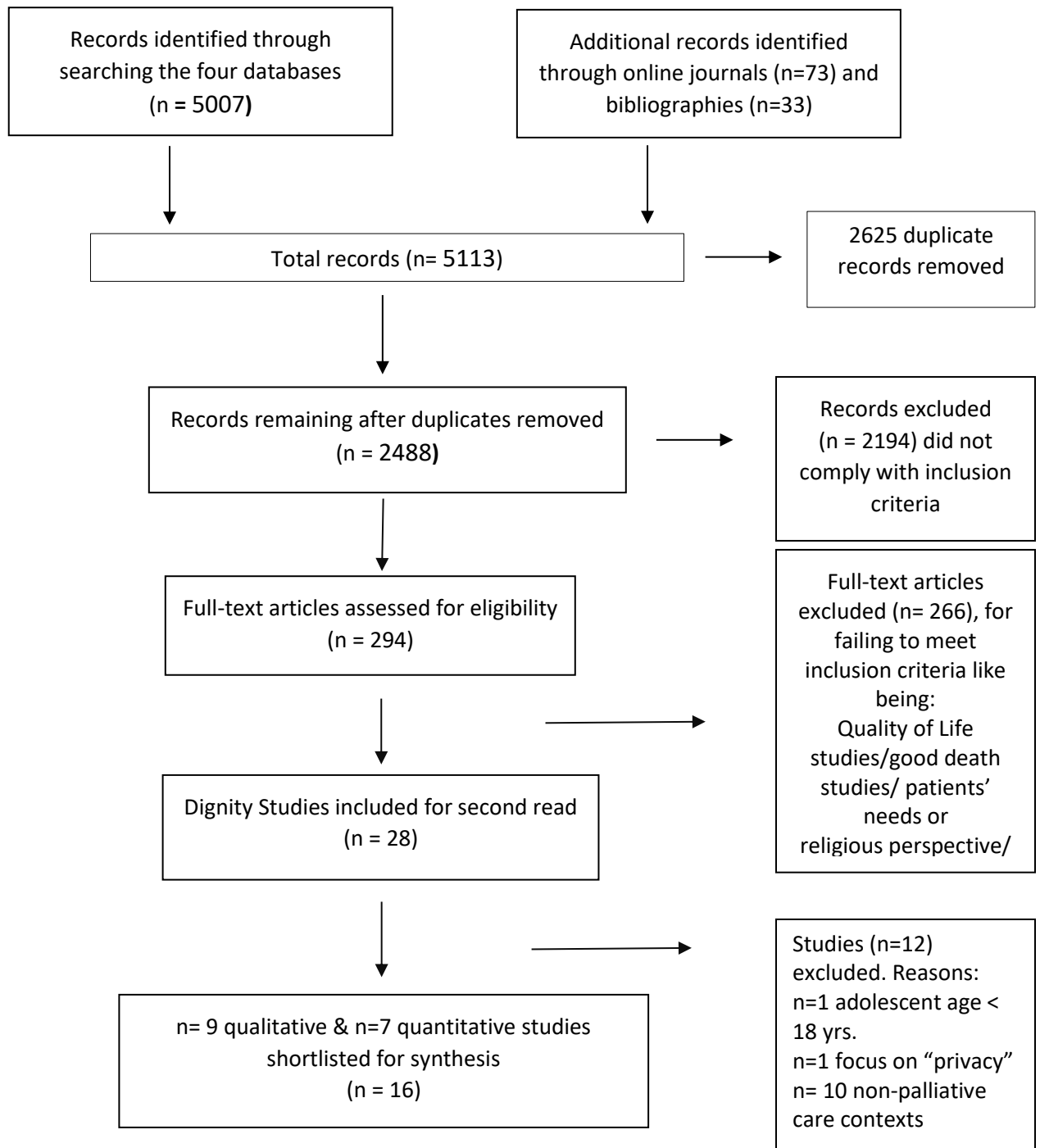


Figure 3. 1 PRISMA Flow Diagram of the review process

3.4 Data Evaluation

The quality of the included 16 papers were evaluated using the Hawker appraisal tool (Hawker et al., 2002). Hawker's tool (see Appendix B) is appropriate to evaluate disparate studies systematically checking study relevance, extracting data, and scoring methodological rigour. Hawker's appraisal tool is commonly used in palliative care reviews because it has broad criteria appropriate for evaluating research from different methodologies and designs, quantitative, qualitative, and mixed (Innes & Payne, 2008; Salins et al., 2020). The protocol relies on a scoring system that ranges from nine (very poor), to 40 (very good), explicitly displaying study strengths and weaknesses by "good," "fair," "poor," and "very poor". Though all the empirical papers were evaluated and scored, no manuscript was excluded for its weak score because appraisal tools may be evaluating the reporting standards of a study and not its methodological rigour (Munthe-Kaas et al., 2019). Thus, the findings of each paper were reported with a critical assessment during the synthesis (Mays et al., 2005).

3.5 Data Analysis

The data analysis stage involved categorising, coding, and summarising the 16 reviewed papers to facilitate the organisation and reduction of the literature. The reports were primarily grouped according to their research design, and those that discussed perceptions of dignity, facilitators, barriers, or health outcomes of dignity. Codes were developed, such as "personal values of dignity", "health care related issues", "communication at end of life", from each paper and arranged in a matrix to allow clear

visualisation and comparison of patterns or variations. The codes were collated so that similar ones, such as the cleanliness of the hospital rooms, private space, quick service, and noise in the units, were assembled to generate a common theme, for instance, health facilities. Non-conforming codes were interrogated to unpick underlying social values like excessive treatment, distress in female patients, or retaining hope in the face of a grave health condition. The analysis was an iterative process involving merging of codes and creating themes and sub-themes to achieve a higher level of interpretation and abstraction (Table 3.6). Seven interrelated themes were developed that incorporated the codes. The conclusion was synthesised by integrating the themes and building a logical chain of how dignity is understood, enhanced or threatened which developed an original knowledge of dignity beyond surface description (Whittemore & Knafl, 2005).

3.6 Findings

3.6.1 Characteristics of the studies

Sixteen papers that represented 14 primary studies were included in the analysis.

Fourteen of them came from the Republic of Iran, one from Turkey, and one from Netherlands that discussed how Turkish, Moroccan, or Surinamese patients understand important aspects of dignity. Fifteen studies were conducted by nurse researchers indicating the high significance of the concept of patient dignity in the nursing profession. Of the 16 dignity papers, 12 focused on patient perceptions, the remaining papers explored nurses', physicians', and hospital staff's perceptions. One paper discussed dignity from the family caregivers' perspective. The patients' medical diagnoses ranged from heart disease (n= 7) to cancer (n= 4) to multiple sclerosis (n=1) and mixed (n= 1). One

study was on patients with end stage organ failure with palliative care needs. Most of the studies (n=14) were published in the past five years, and the rest from 2012-2013, showing that the concept of dignity is evolving in the Middle East and has gained attention more recently. The research designs were quantitative (n=7), and qualitative (n=9) in nature. Most of the qualitative papers (n=7) employed a conventional content analysis method, one paper adopted phenomenology (Korhan et al., 2018), one critical ethnography (Bidabadi et al., 2019) and one thematic analysis identifying a thematic framework (de Voogd et al., 2020). The quantitative studies were all descriptive, or descriptive-correlational in nature. See Table 3.4 for a summary of the characteristics of the 16 papers.

Table 3. 4 Summary Characteristics of the Included Papers (n=16)

Study participants	Most studies (n=12) focused on the perceptions of patients only; two papers studied nurses' and physicians' perceptions: Bidabadi et al (2019), Korhan et al (2018); one on solely nurses' perceptions: Hamooleh et al (2013); and one on patients' & relatives': de Voogd et al (2020). The paper by Borhani et al (2016) focused on patients and hospital staff.
Country of Publication	Fourteen studies were published in Iran only one from Turkey (Korhan et al 2018), and one from the Netherlands (de Voogd et al 2020).
Date of Publication	Most (n=14) publications were during the years 2015-2020; only two were before the year 2015 Bagheri et al (2012) and Hamooleh et al (2013).
Setting	
<i>Cardiac unit</i>	Bagheri et al (2018), Amininasab et al (2017), Bagheri et al (2016), Bagheri et al (2012)
<i>Cardiac Surgery Intensive Care Unit</i>	Bidabadi et al (2017), Mehdipour-Rabori et al (2016), Borhani et al (2016), Borhani et al (2015)
<i>Palliative care</i>	Korhan et al (2018), Hosseini (2017), Avestan et al (2015), Hamooleh et al (2013), de Voogd et al (2020).
<i>Internal medicine</i>	Bagherian et al (2019), Shahhoseini et al (2017)
<i>Multiple sclerosis society</i>	Sharifi et al (2016)

Each study contributed to the synthesis with several themes. The features of the included papers are organised in table 3.5

Table 3.5 Features of the Included Studies

STUDIES FROM THE HEALTH CARE PROVIDERS' PERSPECTIVE				
Author & Country	Purpose	Research Design	Participants/ context	Themes/ Findings
Bidabadi et al, 2019. Iran	To uncover the cultural factors of power that impeded maintaining patients' dignity in the cardiac surgery intensive care unit	Critical Ethnography- Observations; data analyzed hermeneutically and reconstructively	Nurses, physicians, internal medicine specialists, cardiac surgeons, anesthesiologists, auxiliary nurses. Adult cardiac surgery unit	Factors that impeded maintaining patient dignity was Reductionism, Instrumental objectified attitudes. A value -Action gap existed in adhering to the human equality principle. This main theme consisted of two sub-themes: 'authoritative behaviours' and 'Blaming the patients'.
Hamooleh et al, 2013. Iran	The purpose of this study was to explain nurses' perception about ethics-based palliative care in cancer patients.	In-depth interviews using Qualitative Content analysis	Nurses taking care of cancer patients.	Ethical palliative care from the nurse's perspective has three themes: 'human dignity', 'professional truthfulness' and 'altruism'. Human dignity has 3 sub-categories consisting of 'respecting patients', 'paying attention to patient values' and 'empathising'.

<p>Korhan et al , 2018 Turkey</p>	<p>To determine the approach to human dignity that nurses and physicians have while providing palliative care</p>	<p>Phenomenology - Semi-structured interviews using a guide prepared by the investigators. Data analysis was guided by the Colaizzi method.</p>	<p>Physicians & Nurses in the Palliative Care Department of Training & Research Hospital</p>	<p>8 Themes and 43 sub-themes: <ol style="list-style-type: none"> 1. <i>Decision for patients to know their diagnosis</i> 2. <i>Ensuring the quality of end-of-life care</i> 3. <i>Care procedures carried out on patients</i> 4. <i>Adequate provision of medical care services</i> 5. <i>Prioritisation in palliative care</i> 6. <i>Pointless treatment in palliative care</i> 7. <i>Views on the concept of respectful care</i> 8. <i>Views on palliative care</i> <p>The results of the study showed that there was a lack of awareness of ethical, medical, and social responsibilities that led to violation of human dignity.</p> </p>
STUDIES FROM THE PATIENTS' PERSPECTIVE				
<p>Bagherian et al, 2019 Iran</p>	<p>To evaluate the concept of dignity from the perspective of Iranian cancer patients admitted to an oncology hospital</p>	<p>Semi-structured interviews using Qualitative Content Analysis method described by Lundman and Graneheim.</p>	<p>Hospitalised Cancer patients aged >18 years, from the Internal Medicine wards Total of 16 patients; aged 24–70 years (five men & 11 women)</p>	<p>The main themes were identified as, 'personal space and privacy', 'respect for human values', and 'moral support'.</p>

<p>Bagheri et al, 2018 Iran</p>	<p>To determine the relationship between illness-related worries and social dignity of patients with heart failure.</p>	<p>Descriptive- analytic. Two questionnaires used: <i>illness-related Worries Questionnaire (IRWQ) and Social Dignity Questionnaire (SDQ)</i></p>	<p>Total of 130 inpatients (HF) from cardiac wards in 3 hospitals in Iran</p>	<p>The highest mean score of social dignity was associated with the <i>dimension of social communication and support</i>, and the least is attributed to the dimension of a burden to others (economic). Pearson’s statistical test showed a significant correlation ($r = 0.455$, $p < 0.05$) between the score of illness-related worries and social dignity.</p>
<p>Bagheri et al, 2012 Iran</p>	<p>To investigate perceptions of patient dignity and related factors in patients with heart failure</p>	<p>Qualitative semi-structured interviews using qualitative content analysis method described by <i>Hsieh and Shannon</i>.</p>	<p>22 Heart failure inpatients in cardiac wards in hospitals affiliated with Tehran university</p>	<p>Dignity means being considered as a <i>unique human being and being treated with respect and that it means having forgiveness</i>. Factors enhancing or threatening patient dignity were classified into two main categories: ‘patient/care index’ and ‘resources’. Intrapersonal features (inherent characteristics and individual beliefs) and interpersonal interactions (communication, respect, enough information, privacy, and authority) were classified as components of the patient/care index category. Human resources (management and staff) and environmental resources (facilities and physical space) were classified as components of the resource’s category</p>

<p>Bagheri et al 2018 Iran</p>	<p>To investigate factors related to dignity in patients with heart failure and to test the validity of the Dignity Model.</p>	<p>The study had a descriptive-correlational design. Using 4 questionnaires</p>	<p>130 hospitalised heart failure patients. The study was performed in Tehran, Iran. It was conducted in the cardiac wards in urban hospitals affiliated with Tehran University</p>	<p>The results indicate that the research model is fit and acceptable in patients with heart failure, and dignity related factors are in correlation with each other. Social dignity is the biggest factor in the dignity of patients with heart failure. Dignity conserving repertoire and illness related worries (affected by the frequency of hospitalisation and age) also affect dignity.</p>
<p>Mehdipour-Rabori et al, 2016 Iran</p>	<p>It investigated the status of human dignity in patients with cardiovascular disease (CVD)</p>	<p>Cross-sectional descriptive design. Two-part questionnaire to collect data. The first part was a demographic questionnaire. The second part was the Patient Dignity Inventory (PDI).</p>	<p>The study population consisted of 200 cardiac patients hospitalised in CICUs in hospitals affiliated to Kerman University of Medical Sciences, Iran</p>	<p>The findings of this study indicate that there is a significant relationship between gender and emotional problems related to human dignity; women feel more problems associated with human dignity than men. There is a significant relationship between the number of hospitalisations and problems related to patient dignity. Also, statistically significant correlation between living alone and problems associated with human dignity</p>

<p>Amininasab et al, 2017 Iran</p>	<p>To determine the relationship between human dignity and medication adherence in patients with heart failure</p>	<p>Cross-sectional descriptive Data were collected by demographic and clinical questionnaires, Patient Dignity Inventory, and the Morisky Medication Adherence Scale (MMAS-8).</p>	<p>300 hospitalised patients with heart failure on their first day of admission CCU wards of Mazandaran Heart Center in 2016</p>	<p>There was a negative relationship between medication adherence and a threat to human dignity (correlation coefficient $r = - 0.6$, significance level $P < 0.001$). In other words, the higher the score of threat to dignity, the lower the medication adherence.</p>
<p>Shahhoseini et al 2017 Iran</p>	<p>To determine the sources of dignity-related distress from the perspective of women with breast cancer undergoing chemotherapy in Iran.</p>	<p>Cross-sectional study Distresses associated with dignity were measured using PDI. The demographics were also collected via the questionnaire</p>	<p>207 Patients with breast cancer undergoing chemotherapy in Iran from three hospitals of Shahid Beheshti University of Medical Sciences in Tehran.</p>	<p>Patients were mostly concerned about the distress caused by Disease symptoms and the existential distress, peace of mind, dependency, and social support. The patients undergoing mastectomy expressed higher level of social support and dependency distress than patients not undergoing the surgery. Income satisfaction had a significant relationship with Existential Distress and Symptom Distress.</p>
<p>Borhani et al 2016 Iran</p>	<p>To investigate facilitator and the factors threatening the dignity of patients with heart disease</p>	<p>Qualitative semi-structured interview. content analysis constant comparative method with inductive approach</p>	<p>20 hospitalised cardiac patients admitted to the cardiac intensive care unit for more than 48 hours hospitals related to Kerman University of</p>	<p>This study showed that care context is important for patients' dignity and includes human and physical environments; also, safe holistic care (Meeting the Needs of Patients in the Hospital and After Discharge; Creating a Sense of Security) is one of the important aspects affecting the dignity</p>

			Medical Sciences in Iran and 5 personnel in 2014.	of heart patients. If the staff do not perform effective communication (Respectful Relationship, Involvement of the Family in the Health Team) the dignity of patients is not well observed.
Sharifi et al 2016 Iran	The study aimed to investigate factors affecting dignity of Iranian patients with MS in the society.	A qualitative semi-structured interviews conventional inductive content analysis.	13 patients with multiple sclerosis Participants were selected in Iran Multiple Sclerosis Society, and NGO.	Factors affecting patient's dignity can be classified into personal and social factors . Personal factors include the four subcategories of <i>patient's communication with self, patients' knowledge, patient's values and beliefs, and patient's resources</i> . Social factors also include four subcategories of others' communication with patients, social knowledge, social values and beliefs, and social resources .
Borhani et al 2015 Iran	To explore the meaning of patient dignity in Iran	Qualitative- face to face interviews using Content analysis according to Lundman and Graneheim	16 hospitalised heart patients admitted to the cardiac intensive care unit for more than 48 hours two hospitals in Iran, Kerman.	2 main categories; Basic and Transcendent dignity. a) Basic dignity related to physical & psychological health. It is for all patients and must be respected. Subthemes: human security, comprehensive care, education and awareness, respect, effective communication, and privacy . b) Transcendent dignity aims to create a full human with spiritual health. Subthemes: trust, gratitude, appreciation, and spiritual growth

				were included in this category. Some of the participants were not satisfied with the basic dignity alone and were seeking transcendent dignity.
Avestan et al 2015 Iran	The aims of this study were to explore cancer patient perceptions of respecting their dignity and related variables in an Iranian cancer-specific center	Descriptive Correlational The instrument collected demographics and then the Dignity Inventory (PDI) developed by Chochinov in 2008	250 cancer patients admitted to a cancer-specific center In Ghazi Tabatabay hospital affiliated to Tabriz University of Medical Sciences, Iran.	Higher perceived dignity violation in illness-related concerns sub-scale was one of the most important findings of this study. It also revealed that the sense of anxiety and depression, uncertainty regarding the disease and treatments, and worrying about the future were the main symptoms of lack of preserved dignity in this sub-scale.
Hosseini et al 2017. Iran	To assess the association between the status of patient dignity and quality of life (QOL) in Iranian terminally ill patients with cancer.	Descriptive correlational study (PDI) was applied to assess the dignity-related distress of each patient. The Persian version of the (EORTC QLQ-C30) was used for QOL assessment.	210 end-stage cancer patients (102 men and 108 women) All cancer patients were selected from the Seyed Al-Shohada Hospital affiliated with the Isfahan University of Medical Sciences, Isfahan, Iran.	High dignity status in terminally ill patients was associated with higher QOL in terms of functional intactness and lower symptom distress.

3.6.2 Themes

The seven themes, as generated from the analysis, related to the understanding of patient dignity in illness and while receiving care and are described here.

- a) ***Maintaining Privacy & Secrecy:*** Paying attention to patients' privacy during care and being considerate of keeping personal information confidential was seen as respecting patients' sense of dignity. Patients and health care providers agree that having a personal space like a private room in the hospital with separation curtains, personal toilet, a hospital gown that does not expose body parts, is considered essential to preserving patient dignity (Bagheri et al., 2012; Bagherian et al., 2019; Borhani et al., 2015; de Voogd et al., 2020; Korhan et al., 2018). Crowded spaces and proximity to other patients that prevent performing basic self-care activities comfortably such as using the bedpan or washing diminish dignity. Entering patient rooms without prior knocking, particularly when female patients who did not have their head veils in place (Borhani et al., 2015), or loudly announcing frequency of defecation, offended patient privacy (Bidabadi et al., 2019). Unannounced nursing or physician ward rounds were regarded as disrespectful and gave way to indecent body exposure of patients not only in a palliative setting but also in any clinical setting irrespective of specialty (Cheraghi et al., 2014; Ebrahimi et al., 2012). Questions from the nursing staff that probed into the patient's personal life, such as how the illness had impacted intimacy, was regarded to be unethical, rude, and infringing on patient's privacy (Bagherian et al., 2019). Recurrent interactions with health care providers and hospitalisations increased patient vulnerability and the risk of losing personal and physical privacy that threatened dignity (Avestan et al., 2015; Bagheri et al., 2016b; Mehdipour-

Rabori et al., 2016). This could be related to the imperfect health care system and increased vulnerability of the patients.

Maintaining confidentiality of the medical diagnosis and limiting disclosure to a limited number of family members is regarded of the utmost importance to patients (Borhani et al., 2016; Borhani et al., 2015), to the extent that some individuals would deliberately search hospitals that are far from their residencies to maintain discretion (Bagherian et al., 2019). Informing others about their illness carried the risk of stigmatisation or social isolation that risked losing societal status. This was true for patients with chronic non-cancer and cancer conditions. For instance, revealing the diagnosis of cancer or multiple sclerosis placed the patient at risk of being judged or looked down upon by the community, and missing out chances of getting married for both men and women (Bagherian et al., 2019; Sharifi et al., 2016) which were key elements to maintain dignity. Secrecy regarding lifestyle or certain practices, such as the use of opioids in male patients, was crucial to maintain a sense personal dignity (Borhani et al., 2015).

- b) ***Gentle Communication:*** too much pity, blaming, or bluntly disclosing bad news is regarded disrespectful and damaging to personal pride and dignity. Paying attention to patient values, empathising, and delivering what they are ready to hear is considered compassionate and enhancing of dignity (Bagheri et al., 2012; Bagherian et al., 2019; Borhani et al., 2016; Borhani et al., 2015; de Voogd et al., 2020; Hamooleh et al., 2013). Expressions of pity are regarded to be patronising to the patient by affirming the patient's weak position. Patients valued communicating hope and considered it superior to truth-telling, even in conditions of poor prognosis (de Voogd et al., 2020; Korhan et al., 2018).

Blunt disclosure of the diagnosis is undesirable by the patients and health care providers with the belief that maintaining a glimpse of hope promotes patient dignity (Bagherian et al., 2019; Korhan et al., 2018). Abstaining from talking about the seriousness of the condition and believing in the person's predestined fate, surrendering to God's will, is a coping mechanism to maintain dignity (de Voogd et al., 2020). Despite the nondisclosure of the diagnosis, nurses kept informing patients about the inevitable adverse effects of cancer medications like hair loss (Hamooleh et al., 2013) indicating that patients often were inherently aware of their condition, upholding a glimpse of truthfulness. Amid hospitalisation and illness, patients were keen on following their religious rituals such as prayers to preserve their identity and dignity (de Voogd et al., 2020). For instance, a patient was upset to have missed morning prayer due to receiving a sleeping pill the night before (Borhani et al., 2016; Borhani et al., 2015).

On the organisational level, bureaucracy, strict regulations (Bagheri, 2012), and communication that is not driven by patient needs, but is rather paternalistic or routine-oriented, reduces patients' experiences of being valued (Bidabadi et al., 2019). For instance, strict visiting hours, excluding family members, banning the use of telephones, restricting patient freedom undermine the sense of worth and trust among patient and health care providers, consequently diminishing overall satisfaction with care and sense of dignity (Bagheri et al., 2012; Borhani et al., 2016; Borhani et al., 2015). Attentive communication that is engaging, and mindful of individual preferences assures a dignified experience (Borhani et al., 2015). Though communication implies that dignity is a dynamic relational process mediated by social interactions and environmental factors, it is also an individual

perception affected by how one views self-worth and communicates internally with oneself. For instance, self-blame, self-doubt and the belief that the illness is the result of personal deficiencies is harmful, whereas focusing on personal strengths and opportunities promotes dignity (Sharifi et al., 2016). Perceptions of self-value are influenced by the individual's understanding of their purpose in life, relationships to others, religious beliefs, and cultural norms. Faith is either an impetus for expression of resilience or a predisposition to succumb under the pressure of ill health and see its limitations as an unjustified loss that is to be born (Sharifi et al., 2016).

c) **Abundance of resources:** Economic burdens and overshadowing fears of not accessing essential medical resources and health services due to unavailability or inaccessibility are damaging to personal identity and dignity (Avestan et al., 2015; Bagheri et al., 2016b; Bagherian et al., 2019; Shahhoseini et al., 2017). Recurrent admissions to the hospital are associated with high expenses, financial burdens, increased reliance on family support, and heightened patient vulnerability (Avestan et al., 2015; Bagheri et al., 2016b; Mehdipour-Rabori et al., 2016). In contrast, economic prosperity is related to perceptions of being worthwhile, dignified, having a purposeful life, and a meaningful social role (Shahhoseini et al., 2017). Patients with or without palliative needs valued the availability of sufficient medical resources and spacious facilities in the health care system, such as clean and separate lavatories, good lighting, and silence in the intensive care units (Bagheri et al., 2012; Borhani et al., 2016; Ebrahimi et al., 2012). Unequal or disparate care is practiced in times of shortage of resources, where medical staff, especially nurses, become overworked and unable to meet the entire patients' needs (Borhani et al., 2016). Multiple sclerosis

patients who could earn an income despite their disabilities felt more dignified and useful compared to those who were forced to resign (Sharifi et al., 2016). In this regard, education and competencies, such as proficiency of languages, problem-solving skills, were protective to patients' dignity because, amidst physical disability, it secured employment (Sharifi et al., 2016). The inability to sustain economic steadiness is particularly frustrating to the young patients because idleness reaffirmed a sense of unfitness closing on chances of achieving life goals, hence, shattering personal dignity through the inability to provide for oneself (Avestan et al., 2015; Sharifi et al., 2016).

d) Family Support: family caregivers are regarded as a central block of support system to the patient, particularly during hospitalisation for women (Bagheri et al., 2016b; Borhani et al., 2016; Shahhoseini et al., 2017). The patient expects family caregivers to be present, and be included in care planning, and discharge preparations (Bagherian et al., 2019; Borhani et al., 2016; Borhani et al., 2015). Patients who were living alone or lacked a support system from friends and family had a higher sense of disease burden than those who were married or who enjoyed family support (Mehdipour-Rabori et al., 2016; Sharifi et al., 2016). The family offered a social security net, particularly for women, for whom maintaining a social role for instance of a "mother who cooks for the family" was an affirmation to self-esteem and personal dignity (de Voogd et al., 2020).

The role of the family caregiver extends beyond the acute hospital setting to offering care and assistance after discharge (de Voogd et al., 2020). The family members helped patients adhere to treatment and lifestyle regimens, find symptom relief, and seek medical help when needed (Amininasab et al., 2017; Borhani et al., 2016). For this reason, effective

communication between health care providers and patient/family, that entails conveying explanations about the disease and its management, is regarded as crucial to empower the ill individual in making informed decisions and achieving improved outcomes thereby maintaining dignity (Borhani et al., 2016; Borhani et al., 2015; Hamooleh et al., 2013; Korhan et al., 2018; Sharifi et al., 2016). Patients with chronic conditions desire the social environment to be responsive, engaged and understanding to their social needs to uphold independence, security, and wellbeing. A supportive community that empowers patients by offering accessible self-care facilities (Borhani et al., 2015), comfortable housing, safe transportation means, economic stability, is regarded as dignified standards of living and much desired (Borhani et al., 2016; Sharifi et al., 2016).

e) **Physical Fitness:** Functionality and low symptom burden foster patient dignity within the family context (Bagheri et al., 2016a, 2016b; Hosseini et al., 2017). The capability to independently perform daily self-care practices (Avestan et al., 2015), being physically in control of the body, are seen to promote self-concept acting as a protective agent to dignity (Bagheri et al., 2012, 2016a; Hosseini et al., 2017; Mehdipour-Rabori et al., 2016; Shahhoseini et al., 2017; Sharifi et al., 2016). A correlational study by Hosseini et al. (2017) reported that higher physical functionality was associated with lower anxiety, enhanced sense of worth, better symptom control, autonomy, and overall better quality of life in end-stage cancer patients. Whereas reduced physicality diminished privacy, and changes in appearance brought forward feelings of loss of dignity and being a burden on friends and family (Bagheri et al., 2016a, 2016b; Mehdipour-Rabori et al., 2016). Distressing physical symptoms and uncertainty of the health condition seem to be detrimental to mental

wellbeing too, leading to excessive worrying, anxiety, and depression due to the inability to cope with the heightened sense of loss of control (Avestan et al., 2015; Hosseini et al., 2017; Mehdipour-Rabori et al., 2016; Shahhoseini et al., 2017). Thus, focus on psychological and physical symptom management is perceived to maintain dignity in patients with palliative needs (Korhan et al., 2018).

f) **Reliable Health Care:** Expert medical staff with specialised knowledge and who give prompt attention to patients' needs are regarded as essential to dignified health care irrespective of the clinical setting or patient diagnosis (Bagherian et al., 2019; Borhani et al., 2016; Borhani et al., 2015; Manookian et al., 2013). Competent hospital staff members who are diligent, kind and attend to patient needs, despite the unfavourable conditions of the health care institution (high workload or shortage of staffing and resources) are appreciated by all patients (Bagheri et al., 2012; Borhani et al., 2016; Borhani et al., 2015; Cheraghi et al., 2014; Manookian et al., 2013). Time given to assess and talk to patients and not only medicate is vital in the understanding of dignified care (Borhani et al., 2016; Hamooleh t al., 2013; Korhan et al., 2018). Whereas a reductionist approach that objectifies human encounters to medical tasks and body organs instead of a holistic approach fails to protect patient uniqueness and personal dignity (Bidabadi et al., 2019). Safe and error-free services transmit a sense of security and assurance that no harm is incurred to the patient's wellbeing (Borhani et al., 2016; Borhani et al., 2015).

A sufficiently staffed ward that is run by health care providers who appear clean with proper simple attire, was seen to provide an effective and respectful communication that in turn, promotes patient dignity (Bagheri et al., 2012; Borhani et al., 2016). Gender-sensitive

care in the hospital is essential to female patients (Bagherian et al., 2019) as well as preferred in male patients to enable a dignified self-concept particularly when it is related to personal care (Borhani et al., 2015). For patients who were at end of life, maintaining physical needs till the last minute of life such as continuing artificial feeding, body hygiene, and pain management, were regarded highly essential in maintaining the dignity of the dying patient by nurses and patients with heart disease (Borhani et al., 2016; Hamooleh et al., 2013; Korhan et al., 2018). However, blindly following cure-oriented care was sometimes seen as controversial by health care providers and caused personal dilemmas (Korhan et al., 2018).

g) *Social justice:* Patients expect to have just and equal care regardless of low social or economic rank. Being left behind, stigmatised or marginalised due to hardship, foreign nationality, or a medical condition such as addiction or contagious infection, does not resonate with personal dignity (Bagheri et al., 2012). Though health care providers hold a firm conviction and oath of providing equal health care to all (Korhan et al., 2018), there existed a gap between the values and actions of health care providers' where services delivered are affected by consumers' status (Bidabadi et al., 2019). A sense of injustice was reported in Sharifi et al. (2016) when patients with multiple sclerosis, hoped and aspired to have equal opportunities for work, family life, marriage, and non-discriminatory mindset in society that could maintain personal identity and dignity. Humility, mutual trust, compassion, and the gratitude that springs from this altruistic human relationship are sought by patients that is perceived as transcendental dignity (Borhani et al., 2015; Manookian et al., 2013).

Being a female patient with palliative needs increases the emotional distress and instances of decreased dignity (Mehdipour-Rabori et al., 2016). Wives with physical disabilities or weaknesses felt their husbands did not perceive them as complete partners due to their ailment. Some women suffered from disrespect, marital discordance, and had lost intimacy in their relationship (Sharifi et al., 2016). Women often lost their peace of mind for retaining their role as a wife or a mother in the family household (Shahhoseini et al., 2017). Men, on the other hand, felt useless when they lost their jobs or were rejected for employment due to their health condition (Sharifi et al., 2016).

Table 3. 6 Analytical Framework of the developed themes on patient Dignity

Themes	Subthemes	Papers
Maintaining Privacy & Secrecy	<p><u>Enablers</u></p> <ul style="list-style-type: none"> - Personal space/ rooms/ separation curtains - Decent hospital gowns - Knocking at the door before entering patient room - Private space to take care of daily bodily needs - Gender sensitive health care services - Concealment of medical condition and personal information - Secrecy of lifestyle or practices <p><u>Stressors</u></p> <ul style="list-style-type: none"> - <i>Nudity or exposure of body parts during physical examinations</i> - <i>Questioning about personal matters by nurses</i> - <i>Recurrent interaction with health care providers</i> 	<p>de Voogd et al, 2020; Bagherian et al, 2019; Bidabadi et al, 2019; Korhan et al, 2018 ; Bagheri et al, 2018; Madhapur et al, 2016; Borhani et al, 2016; Sharifi et al, 2016; Borhani et al, 2015; Avestan et al, 2015; Bagheri et al, 2012.</p>
Gentle Communication	<p><u>Enablers</u></p> <ul style="list-style-type: none"> - Recognising personal values - Individualised dialogue - Informing the patient about the treatment and required lifestyle changes - Kind & compassionate nursing care - Maintaining /respecting religious rituals during illness and hospitalisation - Gentle disclosure of truth - Retaining a glimpse of hope in health-related dialogues. - Empathy: Being in the patient’s shoes 	<p>de Voogd et al, 2020; Bagherian et al, 2019; Bidabadi et al, 2019; Korhan et al, 2018; Sharifi et al, 2016; Borhani et al, 2016; Borhani et al, 2015; Hamooleh et al, 2013; Bagheri et al, 2012.</p>

	<ul style="list-style-type: none"> - Personal view of self and life - Belief system and relation with God <p><u>Stressors</u></p> <ul style="list-style-type: none"> - <i>Bluntly disclosing the truth about the diagnosis</i> - <i>Excessive treatment of dying patients</i> - <i>Communication that implicates blaming, too much pity, and superior versus inferior relationship</i> - <i>Harassment & abuse</i> 	
Abundance of Resources	<p><u>Enablers</u></p> <ul style="list-style-type: none"> - Affording the medical resources needed - Availability of basic resources and facilities - Maintaining employability - Education, training, problem-solving skills, prior experience - Purposeful life, being worthwhile, maintaining social role - Charity aids - Maintaining a clean environment in the hospital, clean and private lavatories/ rooms, good lighting <p><u>Stressors</u></p> <ul style="list-style-type: none"> - <i>Shortage of health-sustaining needs like medications</i> - <i>Shortage of medical staff</i> - <i>Economic instability & uncertainty</i> - <i>Depending on family and friends</i> - <i>Young individuals are more vulnerable</i> 	<p>Bagherian et al, 2019; Bagheri et al, 2018a; Shahhosseini et al, 2017; Mehdipur et al, 2016; Avestan et al, 2015; Sharifi et al, 2016; Borhani et al, 2016; Borhani et al, 2016; Bagheri et al, 2012.</p>
Family Support	<u>Enablers</u>	de Voogd et al, 2020;

	<ul style="list-style-type: none"> - Presence of family during hospitalisation - Allowing visits - Respect for family caregiver’s needs at the hospital - Family involvement in discharge planning, plan of care, and decision making - Adherence to treatment regimen, symptom relief and ability to seek medical help - Presence of social support when living with family and friends - Sense of medical, physical, and spiritual security - Maintaining social role - Community support to patient / empowering policies <p><u>Stressors</u></p> <ul style="list-style-type: none"> - <i>Living alone</i> - <i>Being cared for by professionals instead of family members</i> 	<p>Bagherian et al, 2019; Bagheri et al, 2018a; Korhan et al, 2018; Shahhosseini et al, 2017; Amininasab et al, 2017; Mehdipur et al, 2016; Sharifi et al 2016; Borhani et al, 2016; Borhani et al, 2015; Hamooleh et al, 2013.</p>
<p>Physical Fitness</p>	<p><u>Enablers</u></p> <ul style="list-style-type: none"> - Physical independence, being in control - Low symptom burden & minimal medical complications - Higher dependence on others deteriorates communication with friends and family <p><u>Stressors</u></p> <ul style="list-style-type: none"> - <i>Recurrent hospitalisation</i> - <i>Uncertainty/ Insecurity</i> - <i>Burden on the family</i> - <i>Stigmatisation</i> 	<p>Bagheri et al, 2018a; Bagheri et al, 2018b; Korhan et al, 2018; Hussein et al, 2017; Shahhosseini et al, 2017; Sharifi et al, 2016; Mehdipur et al, 2016; Avestan et al, 2015; Bagheri et al, 2012.</p>

	<ul style="list-style-type: none"> - <i>Losing social status</i> - <i>Minimising the chances of getting married</i> 	
Reliable Health Care	<p><u><i>Enablers</i></u></p> <ul style="list-style-type: none"> - Expert medical staff who provide error-free care - Prompt attention to patient needs - Comprehensive care that attends to the whole person - Kind nurses - Well staffed and managed ward - Health care providers who are neatly groomed and follow hygienic measures - Sustaining the physical body till the last days of life - Silence in intensive care units <p><u><i>Stressors</i></u></p> <ul style="list-style-type: none"> - <i>Reductionist practice</i> - <i>Lack of motivation from the health care providers</i> - <i>Pointless treatment</i> 	<p>Bagherian et al., 2019; Bidabadi et al, 2019; Korhan et al, 2018; Borhani et al, 2016; Borhani et al, 2015; Hamooleh et al, 2013; Bagheri et al, 2012.</p>
Social justice	<p><u><i>Enablers</i></u></p> <ul style="list-style-type: none"> - Equal care irrespective of social, economic, or medical status - Equal opportunities in life - Mutual respect and trust between patient and health care team - Mindful communication <p><u><i>Stressors</i></u></p> <ul style="list-style-type: none"> - <i>Discrimination</i> - <i>Injustice</i> - <i>Discrepancy between perceived values and the actions of health care providers'</i> - <i>Bureaucracy in the hospital governance/ strict</i> 	<p>Bidabadi et al, 2019 ; Korhan et al, 2018; Sharifi et al, 2016; Shahhosseini et al, 2017. Mehdipur et al, 2016; Borhani et al, 2015; Bagheri et al, 2012</p>

regulations

- *Use of improper language*
- *Paternalistic attitude*

3.7 Discussion

The purpose of this review was to integrate and critically synthesise the knowledge on dignity of patients with palliative care needs and how it is influenced during illness in the Middle East.

Dignity is threatened in illness, in both genders, maybe sometimes more in females, when individuals lose the ability to assert their traditional roles in the family or community (Bagherian et al., 2019; Borhani et al., 2015; Sharifi et al., 2016). Insufficient symptom relief, loss of functionality, and the uncertainty of outcomes (Avestan et al., 2015; Hosseini et al., 2017; Shahhoseini et al., 2017) aggravate the sense of loss of social role.

A patient's personhood thrives within the protected boundaries of privacy, confidentiality, and preservation of sociocultural formalities that nurture a sense of security and dignity (Bagheri et al., 2012; Bagherian et al., 2019; Borhani et al., 2016; Borhani et al., 2015; Korhan et al., 2018).

When consuming health services, personal dignity is fostered by the empathetic and compassionate interaction between the patient and the health care provider. The patient and family expect information about self-care practices delivered in a sensitive way respecting individual values and cultural preferences. Objectifying attitudes, non-engaging, or non-symmetrical communication between patients and health providers are perceived as disrespectful and a major opponent to dignified health care (Bidabadi et al., 2019).

Comparing these findings against the Chochinov's empirical Model of Dignity (Chochinov et al., 2002a), shows overall compatibility to its three domains in that the phenomenon of dignity is affected by illness concerns, shaped by personal outlook and resilience, as well as mediated by social relationships. Loss of physical or cognitive fitness appears to disturb patient dignity irrespective of geographical or cultural setting. Preserving social role and support, seeking

spiritual comfort and the capacity for independent body care protected the pride and dignity of patients. The more the invasion of personal body space by caregivers and the open “uncivilised” discussion of body products such as the number of bowel movements, the more the disruption of privacy and thus personal dignity. Moreover, new themes like economic stability, availability of resources, or themes with a different emphasis like reliance on religious faith, upholding hope for improved health, and the central partnering role of family members in the care of the patient emerged as distinct nuances in the understanding and preservation of patients with serious illnesses. These themes reflect underpinning socioeconomic aspects and cultural values that shape the perception of dignity in illness in Middle Eastern culture. These findings have similarities with the Jacobson (2009b) general Model of dignity that describes the detrimental effects of harsh environments such as deprivation or exclusion on dignity. Self-determination and an individual’s need to control life and death events that is congruent to the dignity attributes in the Western societies (Rodriguez-Prat et al., 2016; Woolhead et al., 2004), is overshadowed with the collective decision making and the prayerful commitment to surrender to God’s sovereignty in controlling the illness and life destiny. In sickness, hope for a divine miracle of recovery or any improvement in health takes precedence to medical management. Gentle disclosure of the prognosis maintains patient’s hope and desire for better health even in futile conditions (Bagherian et al., 2019; Hamooleh et al., 2013; Korhan et al., 2018). Telling the truth about the diagnosis and prognosis, though considered the reasonable practice in the Western cultures to promote patient wishes (Ranganathan et al., 2014), is considered rude in the Eastern Mediterranean region. The unique themes emerging from this review are displayed in a preliminary model of Dignity in Figure 3.2.

The additional themes from this review against the Chochinov Model is displayed in Figure 3.2.

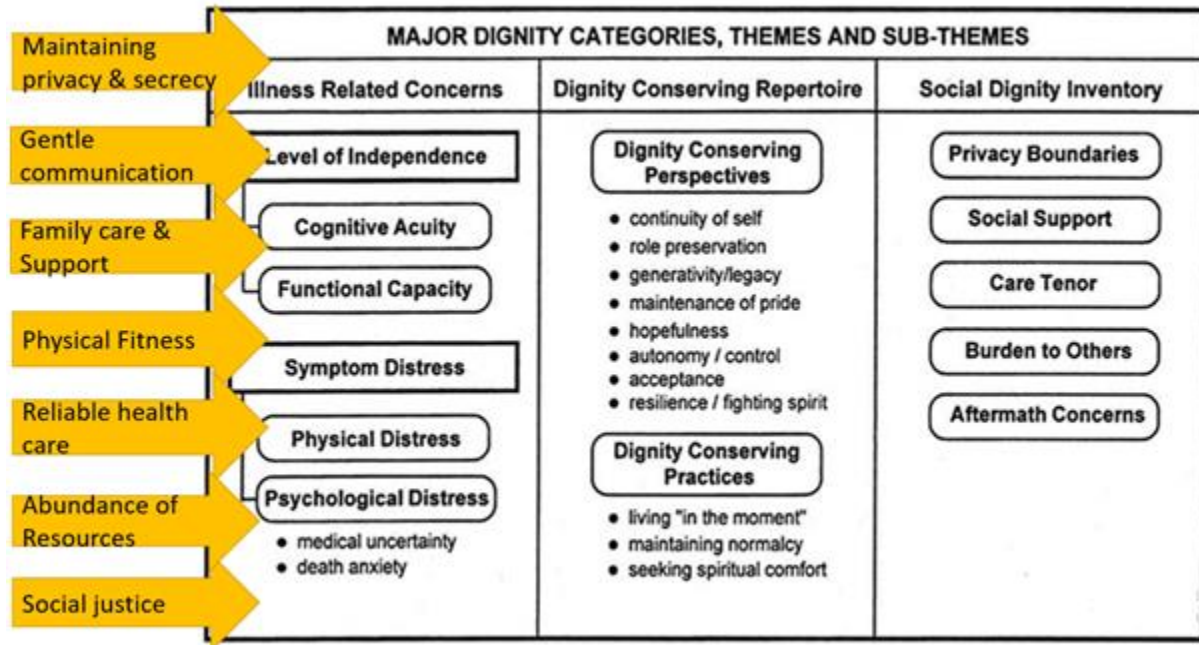


Figure 3. 2 Themes emerged against the Chochinov Dignity Model

The phenomenon of dignity is not equally explored in all countries of the region, and it represents predominantly an Iranian lens that has a majority Muslim-Shia population (UN World Population Prospects, 2019). The Iranian health care system has been under significant funding constraints due to the strict economic sanctions (The World Bank, 2020). This implies that poor political and economic conditions and scarcity of medical supplies deprive patients from attaining full health, leaving them feeling worthless and undignified (Bagherian et al., 2019; Bidabadi et al., 2019; Borhani et al., 2014; Sharifi et al., 2016). Nevertheless, the findings

may also be valid in other Middle Eastern countries where the health care sector is strained due to economic crisis, such as Lebanon, leading to disparities and unequal distribution of health care (Watch, 2019).

3.8 Strengths and Limitations

The strength of integrative reviews is that it allows a comprehensive grasp of a complex phenomenon by combining both quantitative and qualitative research studies. The synthesis clarifies the meaning of dignity in patients with palliative needs in the Middle East by identifying common themes and revealing subtle differences in perceptions that is relevant to culturally competent health care practice and policy.

However, analysing the data and collating themes from diverse sources can be challenging (Whittemore & Knafl, 2005). All the pertinent studies were included regardless of their quality to add to the concept of dignity. Due to restraints in resources, only English language papers were included, excluding evidence reported in other languages. Most of the quantitative evidence is descriptive or correlational reporting the level of perceived dignity and identifying various factors, social and illness related, that affect personal dignity. On the other hand, qualitative papers uncover the personal understandings of the dignity phenomenon without limiting it with questions designed in predetermined tools. Most of the included qualitative studies in this synthesis adopted qualitative content analysis as a tool for data analysis. Content analysis mostly finds meaning through the recurring codes with the application of various levels of interpretations of manifest or latent concepts. It was unclear whether content analysis adopted in the research papers, is applied as a methodology or as a tool in the studies. Hence,

the underpinning philosophical assumptions of the researcher, when explicitly stated in the manuscript, would reflect a better understanding of data analysis and findings (Graneheim & Lundman, 2004; Vaismoradi & Snelgrove, 2019)

3.9 Conclusion

This is the first review that explores the multifaceted concept of dignity in patients with palliative needs in the Middle East. It presents a broad understanding of dignity that allows reflections on how personal, social, cultural, political, and economic forces influence dignity and clinical practice. The studies included mostly explore patients' or health care providers' perspectives on dignity or factors augmenting or diminishing it. There remains a significant gap in the literature in the understanding of dignity from patients, health care providers' and particularly family caregivers' perspectives in the broader Middle East area beyond Iran. This review reveals that cultural awareness like the dominant role of family in patients with palliative needs, culturally sensitive skills such as indirect communications about the end of life, and accessibility of reliable services are essential aspects of personal dignity in some parts of the Middle East.

Chapter 4. Methodology

4.1 Introduction

The aim of this study is to understand how dignity is interpreted in illness and how it is influenced during interactions with health care providers whilst receiving care in a Middle Eastern environment. In this chapter, I will be discussing my philosophical position and the rationale for adopting a qualitative methodology. The data collection methods, sampling strategy, recruitment method, and process for securing informed consent, interview method, data analysis, and quality assurance measures will be outlined in the following chapter of methods.

4.2 Philosophical Position: Epistemology and Ontology

A researcher's philosophical position needs to be consistent with the research question and methodology to generate knowledge that is cohesive and trustworthy (Bunniss & Kelly, 2010; Kivunja & Kuyini, 2017). The term 'research paradigm' is often used interchangeably with the term 'worldview' to define the philosophical lens underpinning the propositions of *ontology*, *epistemology*, and overall methodology of conducting a research inquiry (Mackenzie & Knipe, 2006; Weaver & Olson, 2006). Ontology is the theory of reality, of being and existence, and how we perceive our world exists, whereas epistemology, is the theory of knowledge and how we collect valid and truthful knowledge (Braun & Clarke, 2013). A research inquiry is informed by the paradigm it adopts that in turn has its roots in values, and presuppositions about *ontology and epistemology* (Bunniss & Kelly, 2010; Guba & Lincoln, 1994; Weaver & Olson, 2006). From the various paradigms and research methodologies, this research embraces the constructionist/ interpretivist worldview. The constructionist standpoint focuses on

understanding the human experience by unravelling the viewpoint of the participant and how reality is perceived through the participant's eyes. Reality is socially created through 'meaning-making' reflecting the inner world of the person and the social experiences interpreted through his/her positioning with others (Burr, 2015). The constructionist paradigm diverges sharply from the mainstream positivist stance arguing that social reality or *ontology* is contextual and relative, opposing an ontology of naïve realism, adopted by positivism, that firmly embraces natural laws that are context-free and generalisable (Guba & Lincoln, 1994; Kivunja & Kuyini, 2017; Mackenzie & Knipe, 2006). Within a constructionist / interpretivist worldview the researcher is interested in the unique beliefs, cognitive perceptions and analyses of the participant, appreciating their idiosyncratic nature. The recruit is not a "subject" to be studied from a distance objectively, but a *key informant* or an actor in the social discourse who unfolds the *how and why* of an inquiry (Darlaston-Jones, 2007; Kivunja & Kuyini, 2017).

The concept of human dignity is fluid and based on subjective experience, which is negotiable according to personal values and context (Willison, 2016). In contrast, a conceptual understanding via quantitative measures, a dominant method in positivistic paradigm, may not be suitable in this research, which seeks to capture individual interpretations and nuances of the subject in Middle Eastern palliative care settings. Perceptions of dignity may be multiple, constructed as mental perceptions among the participants through the prevailing social and cultural discourse, where context is part of understanding and generating knowledge (Guba & Lincoln, 1994; Stead, 2004). Thus, the social constructionist lens is suitable because it ascertains that knowledge needs to be explored, *interpreted*, and co-constructed through human interactions and personal experiences (Cohen et al., 2007; Darlaston-Jones, 2007; Goldkuhl,

2012). Social constructionism does not endorse an ontology or a social world that is reducible, deterministic, or generalisable to alternative situations through inferences, but gives importance to contextual diversity, acknowledging the effect of the researcher on the collected data and its interpretation (Burr, 2015; Stead, 2004). Knowledge is not detached from the researcher or waiting to be discovered but can be value laden where assumptions and perspectives are explicitly stated (Bunniss & Kelly, 2010; Kivunja & Kuyini, 2017). Not only do the reported findings reflect personal stories but they are also filtered through the investigator's understanding and interpretation of the data, in the course of the data collection and analysis process (Fink, 2000; Goldkuhl, 2012).

To unveil the *emic*, or inner viewpoint of the participant (whether the patient with palliative needs or the family caregiver) and generate raw knowledge, there needs to be a social interaction between the researcher and the participant in their natural environment.

The *emic* viewpoint reveals the meaning conceptualised in the individual's mind, in their lived experience of a distinct phenomenon within a set of socio-cultural frameworks and prevalent norms. It reveals the inner world of the participant and how he/she understands an experience through the personal lens (Given, 2008). The focus on the individual allows the emergence of variation from the mainstream beliefs giving voice to every participant adding heterogeneity that is not of less value than the universal 'truth' (Burr, 2015; Darlaston-Jones, 2007; Guba & Lincoln, 1994).

Generating knowledge is an inseparable product of the democratised human interaction that gives voice and space to the participant, diluting the potentially dominant or steering role of the *etic*, or external perception of the researcher (Burr, 2015; Cohen et al., 2007; Guba &

Lincoln, 1994). Unlike empirical orientations where the researcher holds the power and may claim an ultimate 'truth' from less powerful 'subjects', in qualitative research there is a reduced power differential between the participant and the researcher. The researcher is open to listening to the participant's perspective, eager to discover the story in its full richness and breadth with flexibility and open-mindedness to diversions from the norm (Nathan et al., 2019). So, truth is not uniform or singular in social constructionist paradigm but affected by the participant within their context; time, place and social interactions (Burr, 2019; Guba & Lincoln, 1994).

The nature of knowledge, the epistemology, in this research is subjective, co-constructed between the researcher and the participant, infused with the community discourse, social order as well as the researcher's implicit values and beliefs, reflecting the inevitable subjective nature of our realities (Burr, 2015). Knowledge is generated through gaining a breadth of understanding of the 'how' and 'why' of the phenomenon, dignity, via eliciting in-depth personal accounts and interviewing that go beyond binary responses. This research is positioned in relativist ontology that resonates with social constructionist theoretical lens, establishing that social realities are necessarily multiple, inter-relational, and embedded in dialect and discourse (Stead, 2004). Dignity is a complex concept associated with power, wealth, rank, wellbeing, skill, and relationships (Jacobson, 2007; Mattson & Clark, 2011), where its meaning can be untangled through the lens of cultural relativism. *Cultural relativism* accounts for the variations of ideologies, human behaviours, and customs that make communities diverse and resourceful. Through understanding the cultural discourses, the researcher can uncover sensitive topics such as patient dignity through the native eye. Cultural

relativism addresses the significance of culture in the interpretation of events and its significance advocating for tolerance to nonconformity without placing judgment (Langdon & Wiik, 2010; Olteanu, 2019). Thus, cultural relativism is in line with qualitative philosophy. There is no universal truth about the qualities of patient dignity in illness to be set as a benchmark to compare against all other 'truths'. Instead, there are variations in attitudes, beliefs, and behaviours, whose meanings are attributed to the underlying cultural systems and social relations prevalent in a society (Liamputtong 2019).

The aim of the research is to understand the interpretations of the concept of dignity in patients with palliative needs in a Middle Eastern Lebanese environment. Thus, it is appropriate to explore this through the social constructionist paradigm, embracing a relative ontology and a subjective epistemology (Bunniss & Kelly, 2010; Burr, 2015; Guba & Lincoln, 1994).

4.3 Why Qualitative Methodology?

A qualitative methodology allows for the exploration and description of personal stories, values, behaviours, and experiences of dignity. Since the research question is not about finding the intensity or the degree of dignity-related distress in patients, nor isolating variables and examining their relationships, or testing a hypothesis, exploratory- descriptive qualitative (EDQ) research methodology is the most appropriate. The EDQ approach allows the researcher to be flexible and creative to describe and interpret the data, strengthening the understanding of the phenomenon of dignity from the participants' worldview (Hunter, 2018). The study seeks to unfold the multiple facets of dignity embedded within the Lebanese cultural foundations without detaching the participant from the natural social setting or controlling external factors.

A qualitative explorative-descriptive design that is fluid and probing is selected because it allows for the interpretation of community norms, practices, and reflections into an integrated meaning and knowledge (Hammarberg et al., 2016). Data generation needs to follow a method that facilitates the participant to express their viewpoint, giving it precedence over the researcher's predetermined set of assumptions. For this reason, a qualitative explorative-descriptive method that allows this fluidity is selected instead of a reductionist one that may overlook the contextual, political, historical, and cultural interpretations of the concept studied (Henrich et al., 2010). The reductionist approach tends to explain complex phenomena through simple forms or tools reducing the effect of the social conditions and culture, that provide a wider relational context and understanding (Stead, 2004).

Qualitative methodology unfolds knowledge through in-depth communication with the participants to attain a rich understanding of inherent assumptions and ideologies of individuals and collective groups (Newman & Clare, 2016). Hence, knowledge generation cannot be completely impartial because it is an inseparable product of the human interaction between the investigator, the participant, and the context (Cohen et al., 2007; Guba & Lincoln, 1994).

The output of the interviews represents raw understanding developed inductively emanating from the unique stories of the key informants (Gioia & Pitre, 1990; Ritchie et al., 2013).

4.4 Reflexivity

A reflexive approach is regarded as crucial in maintaining the rigour in qualitative research. It entails acknowledging the influence of the researcher's views, beliefs, and unconscious biases on the research process, choice of methodology, interpretations, and findings. A reflexive

approach necessitates being transparent about the position of the researcher in terms of gender, race, religion, marital status, work career, political and sexual orientation, education, language, vis a vis the participants. (Bunniss & Kelly, 2010; Dodgson, 2019; Ritchie et al., 2013). I attempted this complex exercise of looking inward and being mindful of my inherent assumptions and influences as a female in her mid-age, married with children, Lebanese, Christian of Armenian descent, with a nursing background working in academia, and a PhD student during the research phase.

My first interest in palliative care awakened when I assisted a senior professor collecting data for her study in palliative care. Having a nursing background and being a clinical nursing instructor was an important aspect that allowed me to be sensitive to how much patients and family members suffered at end of life. Patient dignity was such a fragile and personal topic often unexplored at end of life when a patient is most vulnerable. My views on dignity were particularly stirred when a family member who needed end of life care died without receiving proper attention to dignity. The social constructionist approach resonated with my personal viewpoint as I was aware that human interactions and open communication are the foundation for understanding and caring for patients. Being a nurse, a teacher, and a mother, I felt in depth interviewing was an approach that allows participants to have a voice and state what is important for them. I tried to reduce my hidden biases through sharing my thoughts with my academic colleagues, friends, and supervisors who helped me realise some of my pre-assumptions and quick judgements guiding me to being mindful of their impact. I remember how my supervisor commented on a sentence I had included in one of my writings that talked about women being 'a loving mother and a wife' and how I had unconsciously assumed

gendered roles. With critical reflection, I re-examined whether the developed story and themes were my own story or that of the participant. Reflexivity permitted me to acknowledge the effects of the environment and my personal background on the choices I have made and consequently craft the understanding of dignity, from patient and family caregiver perspective, with humility, transparency and thoughtfulness (Clarke & Braun, 2013b).

After the completion of each interview, I recorded my general impression, highlighted topics, reflections, or any special traits of the participant in my reflexive diary. The reflections were used later in the data analysis process. New or dominant themes in the interview were taken note of for future comparison with other participants.

Chapter 5. Methods

In this chapter, the methods and the approach used to collect data and analyse it for this research are described. It includes the sampling and recruitment strategy, how the informed consent was secured from participants, and why semi-structured interviewing was selected as the tool for collecting data. This chapter also explains the data analysis that uses the Braun and Clark reflexive thematic analysis (2013), as well how the quality and the rigor of the project was assured.

5.1 Data Collection Methods

5.1.1 Sampling

Convenient sampling of participants, who are diagnosed, or cared for, individuals with advanced chronic or terminal illness and willing to communicate their perceptions, or experiences of dignity, was adopted. Convenient sampling was opted because recruitment from institutions was challenging during the Covid-19 pandemic. The research involves two groups of participants: patients and family caregivers. The inclusion and exclusion criteria of each group are defined in table 4.1 below.

Table 5. 1 Inclusion & Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Patient participants	
Adults aged 18 and more since attributes of dignity vary with age (Marvin, 2015)	
Diagnosed with chronic illnesses or terminal conditions such as cancer of organ, tissue, or blood; or organ failures like heart, kidney, liver, lung disease, or progressive neurologic disorders such as Parkinson’s, or autoimmune disorders such as Crohn’s disease, systemic lupus erythematosus and other	Adults who are too ill or too distressed to participate as identified by their physician or themselves.
They have been hospitalised at least once in the past year before data collection. This criterion will ensure patient encounter and interaction with health providers as well as indicate the need for frequent medical attention.	
Capable of conversing in Arabic, English, or Armenian since the researcher can speak these languages fluently.	
Demonstrates no cognitive impairment, particularly dementia and delirium, and can grant informed consent as per the recommendation of the treating physician or nurse. Cognitive impairment would not allow complete and reliable data collection.	
Is willing to discuss personal experiences either in person or via online using social media, or through telephone interviewing.	
Family Caregiver participants	
Adults aged 18+ who are related to the patient with blood ties and identified as the parent, spouse, son, daughter, or a sibling of the patient. Actively involved in the care of the patient for at least in the past 6 months.	Family caregivers who are ill or distressed.
Capable of conversing in Arabic, English, or Armenian.	
Demonstrates no cognitive impairment such as delirium or dementia and can grant informed consent as per the recommendation of the recruiting physician. Cognitive impairment might make it difficult to complete the data collection.	
Does not receive any financial reimbursement for the care giving.	
Is willing to discuss personal experiences either in person or, via online using social medium, or through telephone interviewing.	

Some variation in sampling was sought in terms of gender, age, medical diagnosis, religion, socioeconomic status knowing that perceptions of dignity may change with these factors (de Voogd et al., 2020; Hammarberg et al., 2016). The aim was not to have equal numbers from each category since the selection of participants was by convenience, but differences in characteristics were monitored during recruitment (Palinkas et al., 2015). Heterogeneity of the participants was welcomed to identify the shared patterns in different participants, as well as assess for differences in the perceptions of dignity in patients and family caregivers. (Palinkas et al., 2015).

Data collection stopped once 'rich and thick' information had been gathered from the participants (Braun & Clarke 2016; Clarke & Braun, 2013a). The sample size was dependent on the quality of the interviews and the richness of the knowledge captured in each interview known as 'information power' (Malterud et al., 2016). Once the interviews provided sufficient and in-depth information, allowing the development of shared themes across the data and depicting variability, recruitment stopped (Braun & Clarke 2016; Fusch & Ness, 2015).

Snowball sampling was employed to complete the sample size due to the difficulties in recruiting vulnerable participants during the intense (Covid- 19) pandemic. Snowball sampling is a good strategy to recruit via networking through the initial participant with similar characteristics (Naderifar et al., 2017). So, at the end of each interview, the participant was asked if he/she could think of an acquaintance who could potentially participate in the study. of a potential recruit was discussed with the participant.

5.1.2 Recruitment

Recruiting Patients: The two recruitment sites were a) a home-based palliative care centre that provides free of charge home visits to patients at their end of life, b) an outpatient clinic of a large tertiary hospital that provided services to a diverse population with multiple medical conditions. Hospitalised patients were excluded from recruitment because they are potentially sicker or at an aggravated state of health hindering the capability to afford a private, in-depth interview. In addition, restrictions on patient visitations during the Covid-19 pandemic made interviews in the hospital setting impossible. An invitation letter was sent via email to both centres informing them briefly about the topic and nature of the research. I approached both sites to gain familiarity with the staff and provide details about the study and recruitment method. I met with four physicians in the out-patient clinic who attended to patients with palliative needs and invited them to participate by identifying eligible participants for enrolment. Whereas in the home-based palliative care centre, nurses were the main gatekeepers for identifying and providing access to potential participants. With the restrictions applied to prevent the spread of the Covid-19 such as relying on online appointments or telephone consultations, patients' visitations to the clinic as well as home visits of palliative team to patients were reduced significantly making recruitment challenging.

Due to the pandemic, telephone interviewing was the main data collection method. The telephone numbers of potential recruits were collected from the clinics through the health care team with permission of the primary physician. On the other hand, contacts of potential participants identified through snowballing were collected from the primary participant with the permission of the potential recruit. The researcher called the participants and asked if they

would like to participate in the research on dignity using an invitation script (appendix A). This initial telephone communication paved the way for a friendly conversation with the potential participant (Mealer & Jones, 2014). The participants were given the choice to conduct the interview through a phone, face-to-face, or video call. When potential participants showed readiness to partake in the research, the date of the interview was set that was frequently within a few days of the initial contact. The participant information sheet and the informed consent forms (Appendix C, D, E, F) were sent either via email or WhatsApp as per the participant preference before the interview date.

Data Collection Method: Out of the 29 interviews, 18 were conducted via telephone calls and the rest in person. Telephone interviews are a valuable method of data collection during the pandemic as they safeguard the health of both researcher and participant (Teti et al., 2020). They are cost-effective, with no travel demands, which allows the researcher to contact participants from distant locations. Telephone interviews are also useful for discussing sensitive topics resulting in comparable findings to in person interviewing in eliciting rich narratives (Block & Erskine, 2012; Drabble et al., 2015). A concern with telephone or video call interviewing is excluding those who do not own a phone or missing the in person encounter, emotional cues or the environment the participant lived in (Block & Erskine, 2012). However, evidence shows that participants are more relaxed and emotionally at ease with telephone interviews and willing to disclose personal information, which was evidenced through some of the long and valuable interviews. The flexibility of the interviews and the anonymity of the participants allowed a power balance between the interview and the researcher that counts at the participant's advantage (Azad et al., 2021). Though visual cues were not apparent, special

attention was paid to signals from the speech such as sighs, emphasis, accent, rapid responses, changes in voice, and pauses to enrich the data (Trier-Bieniek, 2012). After the first few telephone interviews, I gained heightened awareness for auditory prompts and adopted active listening for emotions such as anger, surprise, disgust, anxiety (Novick, 2008). Although telephone interviews maybe regarded as inferior to in person interviews, the quality of the data can still be maintained by building rapport with the participant, probing, and creating a safe medium for honest communication (Mealer & Jones, 2014; Novick, 2008).

Eleven interviews were conducted in person during lower intensity levels of the pandemic applying precautions to protect the participants and the researcher's health as per the recommendations of the research ethics committee such as wearing face masks, using hand sanitisers, maintaining a distance between the researcher and the participant, and others (see Appendix B).

Recruiting family caregivers: Most caregivers were recruited directly from the clinics or hospital through the physician's or health care team's recommendations. Some caregivers of interviewed patients were recruited, including individual family caregivers and dyads of patient-family caregiver. Family caregivers were also enrolled through snowballing. The family caregiver participants who wished to take part were sent information about the study details (participant information sheet) and the informed consent to read and discuss before actual data collection (Appendix E, F).

5.1.3 Informed Consent

The informed consent and patient information sheet were sent to the participants through WhatsApp or email and they were given the opportunity to ask any questions before the day of

the interview. Before commencing the interview, the researcher explained the nature of the research to the participants in a transparent way, why and how it is conducted. The duration of the interview, participant confidentiality and voluntariness, the right to withdraw or refuse to participate, risks and benefits of participating as well as interview recording, and storage were detailed. The candidates were assured they had free choice to participate without exerting any coercion. It was made clear that declining enrolment would not result in any adverse consequences that would affect their care or relationship with the institution or physician. The researcher stated that the interview carried minimal risk on their health but allowed the participant space to express personal thoughts or experiences that were untold. Once the participant agreed to proceed with the interview, the date, time, and mode of interview was arranged as per participant preferences. In telephone interviews verbal consent was audio recorded. Written consent was obtained when interviewing in person.

To mitigate risks, very ill or distressed participants were not recruited, and most of the interviews were done via telephone calls to circumvent transmission of Covid-19. A distress protocol (see appendix G) was prepared for participants in case any experienced upsetting feelings during the interview, particularly when narrating unpleasant memories. The protocol was not needed for any of the interviewees as acute emotional responses did not occur. For any mild distress during the interview, the interview was paused allowing the participant to take time to reflect and then resume (Draucker et al., 2009). None of the participants experienced unpleasant feelings to request stopping the interview.

The researcher explained that participant anonymity was provided through the research lifecycle by removing personal identifiers and actual names of institutions or people mentioned

during the interviews. Personal identifiers such as the name, telephone number, recruitment site, home or contact addresses were removed, and pseudonyms were applied to maintain the character of the participant (Toom & Miller, 2017). Confidentiality would only be breached to local authorities when the interviews disclosed actual or immediate harm towards individuals. However, the purpose of the research was intended to be exploratory intending to improve practice and not police any party.

Whenever requested by the patients, family caregivers could be present during the data collection to ensure a comfortable milieu and respect cultural norms (Taylor et al., 2021). A copy of the datasets (audios and transcripts) was kept at the researcher's workplace in an encrypted, password-protected personal computer and will be destroyed once the final report is approved. Access to the collected information was limited to the researcher and the University supervisors.

5.1.4 The Interview

In line with the research methodology, the data collection was conducted through in-depth semi-structured interviewing (Braun & Clarke, 2020). In-depth interviews with open-ended questions can capture the complex sense-making of dignity experiences, which avoids pre-determined close-ended measurements that can narrow knowledge generation (Gill et al., 2008; King, 2004; Ritchie et al., 2013). Language and natural dialogue are essential channels through which thought, events, and reflections are relayed, allowing the co-construction of knowledge within social interactions (Burr, 2015).

Participant observation, use of personal diaries, and focus groups were considered as alternative methods of data collection; however, semi-structured interviewing was found to be

the optimal method in the Lebanese context. The method of participant observation needed ample time and the personal presence of the researcher which was not feasible during the pandemic that mandated isolation and physical constraints. Keeping diaries, though could have been a source of rich data, but it is not a common habit in the Lebanese culture. Focus group discussion was not selected as the topic of dignity was subjective, complex, sensitive, demanding more of one-to-one discussion instead of group experiences. In addition, the pandemic was a barrier to performing group discussions. Thus, individual interviewing, informed by an interpretative framework, was considered the most effective and affordable tool in exploring participant perceptions and beliefs. My nursing background was also very helpful as interviewing was a well-practiced skill (Nathan et al., 2019). Since the research aim was not about constructing a theory on dignity of patients with palliative needs, neither it focused on the essence of the lived experiences, Braun and Clarke's thematic analysis was adopted that is explorative - descriptive and useful in illuminating on an un-investigated topic. Reflexive thematic analysis is suitable to explore and interpret patterns across the data to come up with a central concept of dignity that answers the research question (Braun and Clark, 2013).

The interviews were conducted in an empathetic conversational manner, using open-ended questions and probes. A topic guide (Appendix J,K) devised after an extensive literature review, was used to cover the main areas of the research aim (King, 2004). All participants were asked about their understanding and experience of dignity during their illness and while interacting with health care providers. The researcher encouraged elaboration and clarifications when needed. This method privileges the participant's perspective on dignity facilitating the

narration of experiences and beliefs that are subjective and reflected personal insight. The topic guide questions were kept open and tailored to participant responses with probing for more details on the topic to deepen a richer description of behaviours that diminish or enhance dignity (Nathan et al., 2019). The interview was piloted in the Arabic language with a palliative care nurse and a family caregiver to ensure it used both culturally appropriate language and questions that elicited relevant information. The interviews conducted in person were all done in the participant's house. Only two interviews with family caregivers took place in the hospital setting and the rest at their homes.

During the interview, information about the participant's condition was gathered in the beginning such as the medical condition, age, marital status, and role in the family before asking the participant about the understanding of dignity.

The interviews were completed in English, Arabic or Armenian languages as per the participant speech fluency. They were audio recorded and then directly translated into English and transcribed verbatim including pauses, laughs or other gestures to provide comprehensive context to the data. Paying attention to changes in the tone, voice, and narrative content by demonstrating appreciation to the participant contribution was important to maintain connection and remain engaged throughout the interview (Drabble et al., 2016). Words that were stressed were underlined, three dots were used for pauses, non-English terminologies in Arabic or Armenian that did not have an accurate translation were kept in their original language to preserve the contextual meaning.

To ensure quality of the transcription the first transcribed interview was sent to the research supervisors for their feedback.

5.1.4.1 The Use of Multiple languages

Since multiple languages were used in data collection, English, Arabic, or Armenian as per the participant preference, attention was paid to maintain rigour and not lose the true meaning of the content through translation. Traditional methods of forward and backward translations were not applied as it would leave a gap in seizing the conceptual meaning of the narrative and safeguarding its cultural nuances (Larkin et al., 2007). Instead, the researcher revisited the interviews and the transcripts several times in their initial language during translation, used alternative words / synonyms or phrases in the translation, observing for grammar and syntax to enhance cultural congruence of the translated data (Clark et al., 2017). During first phase of the interviews, because the topic of dignity is illusive, several synonyms of the word was employed to ensure that the concept is well understood by the participant. The same wording adopted by the participant was followed throughout the interview to maintain mutual understanding (Larkin et al., 2007). Often certain phrases were kept in the original language because either an equivalent of the word in English were not found or translating it would lose meaning. The aim was not word by word translation to maintain linguistic equivalence but rather interpretation of the content vigilant to maintaining conceptual equivalence and close similarity of what is expressed with the translation (Clark et al., 2017; Smith et al., 2008).

5.1.5 Research ethics

The study follows the ethical guidelines set by the Economic and Social Research Council (2015).

As the research was conducted in Lebanon, ethical approval was secured from the American University of Beirut Institutional Review Board and also from the Lancaster University Faculty of Health & Medicine Research Ethics Committee (FHMREC). The primary research proposal was approved to conduct in person interviews, but because of the Covid-19 pandemic the data collection was amended to include telephone calls or video conferencing, which delayed the start of data collection by six months. The research project received no funding.

5.2 Data Analysis

Coherent with the qualitative philosophy and its values that embrace researcher subjectivity (Braun & Clarke 2019), reflexive thematic analysis was chosen as the method for data analysis because it allows for a dense and detailed account of personal experiences. Reflexive thematic analysis is flexible and suited to be applied with the constructionist paradigm because it supports the underpinning values of a qualitative philosophy where knowledge is conceptualised within the sociocultural context and researcher reflexivity is a core value (Braun & Clarke, 2006; Braun & Clarke, 2014; Braun et al., 2019). Reflexive thematic analysis advocates the use of systematic and thorough coding that is loose and iterative, without following a predetermined coding framework or codebook with the aim of understanding experiences and behaviours across the data (Braun & Clarke, 2020). Hence its appropriateness in exploring the complex concept of dignity. Reflexive thematic analysis relies on the researcher's interpretation to generate themes after interrogating the semantic (surface) data and uncover its implicit (latent) meanings, contradictions, and social implications. So, in coding and data analysis, the researcher's personal mark is inevitable. Nevertheless, credibility is maintained through

transparency of choices including the researcher's reflection and internal examination of personal and social positioning that could have affected the findings (Braun et al., 2019; Clarke & Braun, 2013b). This was carried out by keeping a reflexive diary where I was challenged to explore my role as a healthcare worker and a nursing instructor, and the effect it has on my own understanding of dignity and its implications on patients. This self-awareness and introspection of personal thoughts, particularly as a novice researcher, increases the quality of the research and contextualises it providing transparency (Dodgson, 2019).

The outcome of reflective thematic analysis is a set of themes revolving around a central story of dignity that emerges after long-term engagement and interpretation of the data. The story connects the developed themes in a logical sequence responding to the research question of understanding dignity in patients with palliative needs.

Reflexive thematic analysis can be carried out inductively, where the themes are rooted in the data, or deductively using a theoretical lens (Kiger & Varpio, 2020). In this study, I have used an inductive method where the themes are data-driven purely representing participants' voices rather than honing down to compare the raw data with a theory or a framework. The process was reflexive and recursive requiring frequent revisions to the delineated steps and refinements (Braun & Clarke 2019; Braun & Clarke, 2020; Clarke & Braun, 2013b; Clarke & Braun, 2014).

The translated transcripts were uploaded to NVivo qualitative data analysis software version 11. Though the coding was developed and applied by the researcher the software facilitates organising the data, visualising connections and the running story without replacing the researcher's creativity or interpretation (Sotiriadou et al., 2014). The analysis was data-driven,

searching for codes openly without using a priori framework. A line by line coding process was applied remaining loyal and close to the words used by the interviewees (Braun & Clarke, 2006). The subsequent six steps identified by Braun et al. (2019) were employed. The analysis steps followed in this review are explicated in the below table.

Table 5. 2 The Analysis

Step	Action
Familiarising with the data	I listened to the interviews few times and transcribed them on word document on my personal computer noting down initial ideas and impressions. The sounds, giggles (indicated as “ha-ha”), pauses (indicated by “...”) or emphasised words (underlined), were transcribed.
Generating codes	After listening to the audio-recordings and reading the translated transcripts multiple times I marked codes that were apparent in the content, or represented an underpinned value related to the research question. This step was iterative generating over 100 codes related to patients or family caregivers’ experiences and perceptions of dignity across all the interviews.
Constructing themes	After coding all the interviews, I started to work with the patients’ interview text first collating similar codes into initial themes and sub-themes. After repeated analysis, contemplation, and review, four potential themes were developed. Once I finished with patient participant group, I commenced collating the codes from the family caregivers’ interviews to develop themes. The groups were analysed separately to identify similarities or differences in the themes.

Revising the themes:	Here I rechecked the codes under each theme to see if they make sense and compared them with the interviews. I explored for other possible themes or nuances related to a central concept. Here the interviews were reviewed to see if the themes appear across the data.
Defining and naming themes:	The process was an ongoing analysis to refine each theme, ensuring they tell a story coherently in relation to the research question. Till the last-minute themes were defined and named and interview recordings revisited to ensure they capture the raw data.
Producing the report	I started the write up, defining each theme and creating boundaries, ensuring they did not overlap. I selected vivid and compelling extract examples of data to support the themes relating them to the research question and the literature. Although this is the final step of data analysis, the report was reread for few times and the themes were renamed, revisited, and refined adding, editing or deleting quotes.

The steps of analysis were non-linear but iterative involving interrogation and reflection examining tensions with regard to age, gender, power, societal values and cultural norms. It was time consuming to arrive to themes that were rich, interpretive with high level of conceptualisation that reflect hidden societal realities and implications.

5.3 Quality Assurance

For good quality research it is important that the design and method adopted is fit to answer the research question. The formulation of the research question, sampling method, data collection and analysis are well articulated with full explanation of why they were chosen (Kalu,

2017). Clear description of the embraced ontology, epistemology, and methodology and the rationales of those decisions with knowingness is practised to assure the credibility of the qualitative research (Braun & Clarke 2019). Transparency and clear articulation are key in maintaining the quality and rigour of the research project (Braun & Clarke 2019).

The researcher's prolonged engagement with the data through reading the interviews several times even after the completion of the write up, increased the researcher's insight into the context, minimizing misinterpretations. The research findings are about human stories that resulted from prolonged immersion of the researcher in the data, analysis process, and thoughtfulness. Seeking the feedback of scholarly colleagues, supervisors and debriefing the findings to them, also allowed to researcher to reflect, contemplate, and improve the quality of the findings.

Transferability, or the applicability of the findings to other contexts or settings, is appreciated and realised when enough detail of each research phases is provided so that the reader can identify with the findings in their local environment (Kivunja & Kuyini, 2017). All the interviews were conducted and analysed by the researcher. The Lebanese context was well described, and each theme was supported with several excerpts to provide a full and elaborate understanding to the reader. The thick description of the research phases allows any outsider to make the judgment of transferability to their own setting (Korstjens & Moser, 2018). Transferability is also maintained when the research findings are compared and assessed against the literature evidence by using references and established theories (Kalu, 2017).

In line with the philosophy of this research, researcher subjectivity, creativity and reflexivity hold a central stance in generating knowledge in contrast with the structured method

employed in more positivistic approaches. Reflexivity has a central role in qualitative studies advocating for an explicit account of the researcher's philosophical framework and position. Thus, the researcher kept a reflexive diary jotting down impressions about the participants, the interviews, the context, and overall research journey with the encountered challenges. The positionality of the researcher is explicitly stated to enhance transparency and convey a deeper understanding of researcher's background.

The 15-point checklist (Appendix M) criteria for good thematic analysis set by Braun and Clarke (2006) is referred to and adopted during data coding and analysis. The checklist entails diligent transcription, thorough coding that is inclusive of every item. The developed themes are rechecked against the original data ensuring they are well grounded in the data, stand alone and make vital components of the narrated story. Time is dedicated to this process to ensure the research findings are rigorous and trustworthy.

5.4 Conclusion

After exploring the different worldviews, qualitative methodology was found to be the best choice for undertaking this study as it generated meaningful data from patients and family caregivers. The chapter describes the methodological paradigm as well as the method of data collection, recruitment strategy and data analysis. It explains how reflexivity is a central tenet of analysis and rigour in qualitative research. The findings obtained from the analysis are described in the following two chapters.

Chapter 6. The Findings from the Patients' Interviews

The four themes developed from the 14 interviews with patients experiencing advanced chronic and terminal illnesses are presented in this chapter. Participants' characteristics are described briefly following a detailed elaboration of each theme supported with participant quotations. A thematic map displaying the developed themes and sub-themes is presented. The first three themes a) Faith, b) Family and Children, c) Physical mental and social wellbeing are related to the participant's resources that support dignity. The fourth theme of compassionate and comprehensive care sheds light on maintaining dignity while receiving health care services.

6.1 Participants

Fourteen patients with various advanced chronic conditions such as organ failure or cancer were included in the study. The demographics of the participants are presented in Table 5.1. Pseudonyms are used to protect the identity of the participants. Participants came from various religious backgrounds such as Muslim or Christian as well as sects of these religions such as Sunnis, Shias, Druze, and Armenians. The interviewees lived in Beirut, or the suburbs and their age ranged from 45 to 93 years (mean 68 years). All potential participants identified at the recruitment sites agreed to be contacted and accepted to participate in the project. All interviewees, except one who was very sick, were willing to talk about their experiences without any constraints. The interviews were conducted between September 2020 and April 2021. The recruiting took more time than anticipated due to the Covid-19 pandemic restrictions that prevented patients from attending the clinics. For this reason, enrolment of participants from the home-based palliative care centres was minimal, due to them having to shield at

home, coupled with the difficulty of these patients to talk for long hours on the phone owing to the impact of their illness and fatigue. Thus, most participants came either from the hospital outpatient clinic or through snowballing.

Four interviews were conducted in person at the participants' request in their homes in accordance with Covid-19 protective policies during non-lockdown periods (appendix D). The rest were performed by telephone. The interviews lasted from 5 minutes (this participant rapidly became too tired) to 79 minutes with a median of 38 minutes.

Table 6. 1 Participant Demographics

Pseudonym	Interview method	Age	Marital status	M/F	Diagnosis	Religion	Recruitment route
P01 Sam	In person	67	Married	Male	Cancer	Muslim	Home based palliative care center
P02 Rima	Telephone	81	Married	Female	Chronic Obstructive Lung Disorder & Heart failure	Muslim	Outpatient clinic
P03 Mo	In person	77	Married	Male	Kidney failure on dialysis	Muslim	Outpatient clinic
P04 Camal	Telephone	73	Married	Male	Hypertension, diabetes & cardiac	Christian	Outpatient clinic
P05 Elie	Telephone	67	Married	Male	Blind, stroke, cardiac	Christian	Outpatient clinic
P06 Zein	In person	93	Married	Male	Hypertensive, coronary artery disease	Christian	Snowballing
P07 Suha	Telephone	64	Widowed	Female	Breast cancer	Christian	Snowballing
P08 Viviane	Telephone	83	Single	Female	Severe arthritis	Christian	Snowballing
P09 Lea	Telephone	45	Married	Female	Leukemia	Christian	Snowballing
P10 Chams	Telephone	47	Married	Female	Cancer of the Thymus	Christian	Snowballing

P11 Ella	Telephone	66	Married	Female	Kidney transplant with skin disease and dental necrosis; Mediterranean fever	Christian	Snowballing
P12 Sara	Telephone	65	Married	Female	Tuberculosis with pulmonary fibrosis	Christian	Snowballing
P13 Mary	Telephone	68	married	Female	Brain tumour	Christian	Snowballing
P14 Nelly	In person	52	Married	Female	Breast cancer	Christian	Snowballing

6.2 Themes

Four themes and 13 sub-themes were developed in response to the research question (see table 5.2). The four themes describe the perception of dignity and how it is enhanced during advanced chronic and terminal illness in palliative care patients. The first two themes describe how patients use faith, family/children for support as resources to enhance and validate dignity. Enjoying minimum level of physical, social, and mental wellbeing is the third theme for supporting dignity. The final theme explains the impact of health care services on patient's dignity describing the need for compassionate and comprehensive health services to safeguard dignity. Thematic mapping is found in figure 5.1.

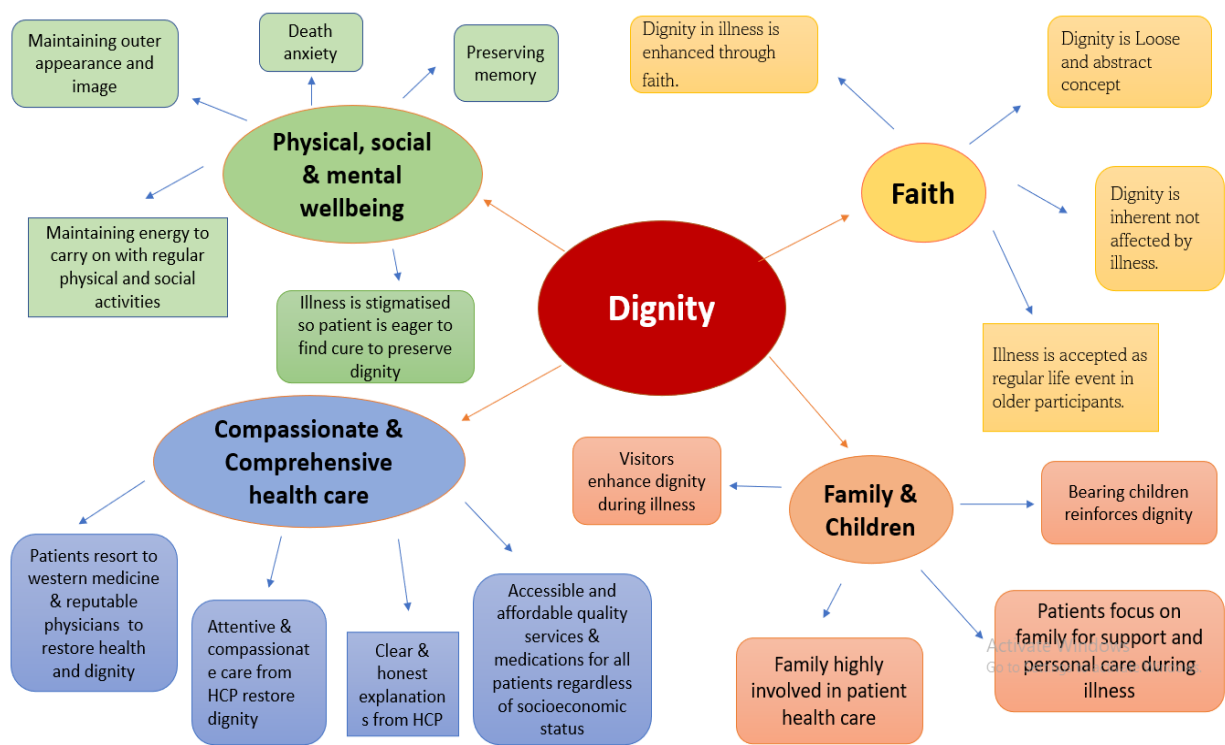


Figure 6. 1 The thematic mapping of the themes and subthemes revolving around the understanding of dignity through the eyes of the patients. The central theme of dignity is situated in the middle supported by four themes: Faith, Family and Children, Physical, social and mental wellbeing, Compassionate and comprehensive health care. Each of the four themes encompass sub-themes clustered with the same background colour.

Table 6. 2 Themes and supporting sub-themes

Faith	<ol style="list-style-type: none"> 1. Dignity is a loose and abstract concept. 2. Dignity is inherent not affected by illness. 3. Dignity in illness is enhanced through faith. 4. Illness is accepted as a regular life event in older participants.
Family and Children	<ol style="list-style-type: none"> 1. Bearing children reinforces dignity. 2. Patients focus on children and spouses for affectionate support and personal care during illness. 3. Family highly involved in patient health care. 4. Visitors enhance dignity during illness.
Physical, Social and Mental Wellbeing	<ol style="list-style-type: none"> 1. Maintaining energy to carry on with regular physical and social activities. 2. Preserving memory. 3. Maintaining outer appearance and image. 4. Illness is stigmatised so patient is eager to find cure to preserve dignity. 5. Death anxiety.
Compassionate and Comprehensive Care	<ol style="list-style-type: none"> 1. Attentive and compassionate presence from health care providers restores dignity. 2. Patients resort to Western medicine and reputable physicians to restore health and dignity. 3. Clear and honest explanations from health care providers. 4. Accessible and affordable quality services and medications for all patients regardless of social or economic rank.

6.2.1 Theme One: Faith ‘I have my faith you know... whatever will happen will happen’

This theme outlines the fluidity in understanding the nature of dignity and how it is enhanced through faith, religious beliefs and principles as viewed by the participants. Whenever patients were questioned about their perceptions of dignity, many did not have a direct answer, were uncertain about the meaning and requested more explanation. Some did not comprehend the question and were prompted by the interviewer with examples or life situations for elaboration. The researcher used different synonyms, rephrasing the question, or sometimes giving examples of patient dignity from the literature. This difficulty in understanding or

immediately answering could be related to the impact of the language on the word of dignity translated as 'Karamah' in Arabic or 'Badiv' in Armenian and the connotations the concept may carry in the used language and culture. However, the participant's understanding of concept of dignity was ambiguous, abstract, and hard to define regardless of gender, language, or ethnic group. Some participants said that the word was loose, with multiple facets and difficult to encapsulate. Others explained that dignity is something felt *within* the self, associated with emotions.

- *'I don't know "ezet nafs" (self-esteem) and dignity are so vague and can't be defined and limited. It represents your inner being and world.... I do not know.... If you want, ask me more specific topics and I can answer.'* Chams

The concept of dignity appeared opaque to some participants, as they did not necessarily relate the concept to that of health. Dignity had an inherent feature preserved in the person regardless of infirmity. Illness was regarded as a natural occurrence in life, something that anyone may experience without causing changes in personal dignity. Some participants even signalled that illness is predetermined from the creator, and that the almighty God is in control of everything, the source of offerings as well as losses. Many participants accepted ill health as one of the challenges of life that one may regularly confront. However, those of a younger age were surprised and did not receive their diagnosis smoothly.

- *'No, no for me dignity is not affected by illness, they are not in the same boat.... Dignity for me has a different stance, different understanding. Illness is completely something else, why should it affect/ damage with dignity?'* Suha

Participants stated that dignity is understood as a concept that revolves around the inner self, your character, and is something to be protected. Its value is unchanged by gender, schooling, social status, or health, because human beings are worthwhile as an end and dignity is inherently maintained as an integral part of the person even after death. The dignity of the individual is enhanced through faith and loyalty to the Almighty. It is cultivated through demonstrating devotion to the virtues and ethical values inscribed in religious scripts whether Muslim or Christian, establishing a closer link between the moral individual and divinity.

- *'No no, I have taken these things (illnesses) as regular things, and first of all I have my faith you know. Whatever will happen will happen, what can I do...'* Ella

Participants expressed consolation and a safe refuge of their dignity in their faith in God. God is perceived as the omnipotent presence, the source of life and good. Through prayer, watching religious television programs, singing praises, reciting verses, and participating in WhatsApp spiritual group communities, participants evoke a sense of hope and wellbeing fostering their dignity. The hardships of living with chronic or terminal illnesses are coped with through prayer and trusting God who listens to the sufferers. Even amid the difficult cycles of relapse, individuals could see “miracles” happening and the “hand of God” arranging life circumstances to their own personal good. For instance, one of the participants expressed that even though her cancer came in the prime of her life, the timing of her chemotherapy sessions was planned by God to protect her from the devastating Beirut Port explosion. Many believed that illness happens as God’s will, and they could not change it. God was comprehended as the source of deliverance as well as the controller of events. Faithfulness to the divine was readily expressed especially in the minority sects of Armenian participants regardless of gender. Even though

some participants could not pray for their health during illness because they were too unwell, they asked community members to pray on their behalf for their healing.

- *'It was not a personal or lonely struggle with the medical condition, but I felt that someone, the Lord, was with me... and the dignity I received from my faith made me feel that someone is with me, I am not alone... there are things that cannot be fully expressed in words... you just feel them, you feel the presence of the Lord with us.'* Chams

During personal struggles with the terminal illness, participants restore their dignity by finding strength and power in the divine through spiritual faith. As the data collection was conducted during the pandemic some participants thought that this was a period for contemplation, to turn to their Lord pleading for guidance, love, unity, and tolerance as 'no one is big except for God'.

- *'Now in the times of corona, I am asking the lord, Dear lord, help us live with love of each other that you taught us.... Because if we are united, help out one another, without hating, or stealing or holding grudges, or fighting with each other, all this is not worth it. Corona showed to us that no one is big except for God.'* Viviane

6.2.2 Theme 2: Family and Children 'Thank God I have my Children'

Patients explained that family members, children, and their relations are the building blocks and the pivotal social net where dignity is safeguarded during illness. The interviews reveal that living in or establishing a family and bearing children are core societal values that reinforce individual dignity. According to patients, being surrounded by family members and children is considered a loving shield, protective against physical and psychological threats to dignity. Children are regarded as the legacy of the participants to whom they pass on their values, 'wisdom', and stories, finding fulfillment in personal honour that enhances dignity. It is a common aspiration to thrive to maintain cordial family dynamics and respectful relationships

amongst extended family members, in order to maintain close connectedness and warm relationships. Large families are a source of pride, where men are regarded as the head of the family and women, the mother is the primary social organiser, source of compassion, kindness, and love among the members.

*'Of course. Pardon me, my children graduated from universities, and got employed, but it was not enough. So, they went to America and my eldest son got married and he has kids now (a boy and a girl). And my other son also got married but has no children yet'.
Elie*

*'My wife and children are very good hamdellah, and I live with them. My wife is also very good, she takes care of me ... My children are with me, my wife is near me and I own a house (an apartment) and the children do for me whatever I need, you understand ?'
Camal*

Married participants take pride in their children and those with no children, celebrated their own personal successes, their education, and involvement in the community as their source of pride reinforcing dignity. In line with the fundamental significance of family in an individual's life, their presence during hospitalisation around the patient is perceived as of utmost necessity. The family's presence feeds into the patient's identity, social status, worth, and dignity. When the patient is in a vulnerable condition, such as during hospitalisations, the husbands, wives, or children take over discussing the medical condition, or even plan the care of the patient, as this is regarded a filial duty springing out of love, caring and compassion.

- *'Dignity will change when the person does not have a family to dignify him/her and take care of him ..., this is when dignity changes. However, thank God, I have my children, they work, and they are employees, so they preserve my dignity. Thank God' Rima*

- *'yes, I forget everything, but they (my children) are above all, they are the most important thing for me, especially that I have my condition, for me, my family is the most important thing' Suha*

A loving partner, a husband, or a wife, who assists in their daily needs, and is loyal and empathetic towards the patient is a major source of support to boost the dignity of the patient. Caring for the patient or handling the basic daily needs (washing clothes, maintaining personal hygiene, ensuring a nutritious meal) without showing that the patient is a burden on the carer, wraps the patient with a sense of security and warmth. This tolerance demonstrated towards the patient during their illness conveys a sense of inclusiveness, belongingness, and acceptance despite the infirmities of the patient.

- *'My husband's extensive support for me was first, my friends who were always ready to be of assistance ...all of these summed up, gave me hope.... I always sing this "Love held me high" [sern vertzouz zis]" the love that I enjoyed surrounding me was amazing'*
Nelly

In contrast, a husband, or a wife who is distant, non-caring or not involved in the care reduces dignity and is even a source of distress. Therefore, often, family members take over the planning and implementation of the care of the ill patient. This entails making medical appointments, communicating with the health care team, securing medications, and following up with health care providers about need.

- *'even my husband didn't take care of me, neglected me "ma tallae feyye" (he never laid eyes on me), I was trying to support my back and my lungs were hurting as if I am holding one ton of heaviness on my spine, and at the same time, I have to do my house chores, I needed to go up and wash the dishes and my tears filled my eye (dmooeei aala aaynayye), ...So, I did not find any help from my husband ' Sara*

Having visitors at times of illness is appreciated, as it is a sign that the ill person is respected and

is missed in the social circle. Family members, as well as extended family or friends living abroad, come over to visit and support the ill person. This is a cultural custom that bears the meaning of reciprocity in caring, courtesy, and kind attention to the sick.

- *'Honestly, the negative part of my sickness I did not focus on; but the positive parts were my children, my sister, my husband, even hmmm my daughter from the states came to visit me. She said she felt through the phone call that I am not doing well.'* Mary
- *'it's not only that my brothers came over from Europe to visit me, I tell you all the whole neighbourhood came over for a visit. All the neighbourhood was here. If they don't respect or care for me and I don't respect them, do you think they would have come to see me?'* Sam

In this regard, a participant who felt isolated from friends due to physical weakness or inability to go outside, or their friends had passed away, was disheartened, and felt that they had lost purpose in life and that living a long life without seeing family or spending time with friends is useless.

- *'I have been at home for years. why? My friends are all dead. Where do I go? And this has affected me.'* Zein

During the pandemic, the most damaging impact to patient dignity was the restricted patient visitations in the hospitals. Patients felt isolated or neglected in the hospital, which affected their self-esteem, morale, and ultimately dignity.

- *'It had been the 5th day of my hospitalisation and I hadn't had anyone visiting me... this behaviour from the nurses was so bad, as if we were animals.... This was not right. This didn't help me to improve in health.'* Chams

Even when personal visits are not possible, communicating through smart phones or online applications is perceived essential to stay connected.

- *'I spend my time with praying, and I use the cellular/ mobile, I am happy to have it. I send WhatsApp messages to my friends. I send news and updates to my friends; I send them important sections of news or articles written related to Lebanon. I remove the advertisements from them. I send to my Armenian friends separately, then Arab friends then those who are in the USA. I edit the news and send each group different ones according to their preferences. This is how I spend my time' Ella*

6.2.3 Theme 3: Physical, Social and Mental Wellbeing' changed upside down...'

Patients aspired towards restoring their physical fitness, normal life, mental and social

wellbeing, symptom relief and cure. They hoped to escape from illness and its attached stigma, to reinstate normalcy, and restore dignity. Preserving physical energy and functionality were one of the shapers of dignity in illness. The ability to move around, walk, take care of personal needs independently (toileting, bathing, eating), be symptom free, pursue a career, go to outings for relaxation or pleasure were other core elements of feeling dignified. This implies that comfort and a manageable level of pain to enjoy physical autonomy and pleasant social interactions is a precondition.

- *'The things that changed in me are ... what can I say...I changed upside down. I was a gentleman, I loved going to trips, to have fun, I love enjoyment and partymy condition is not the same now it turned upside down. This is the truth...I used to walk from here (cheifat area) to Beirut governmental hospital and come back on my feet. It's not the same now.'* Sam

Memory loss or confusion is a barrier to maintaining dignity as it takes away not only the ability to make decisions, but also, the capacity to start a meaningful conversation or socialise with others. As expressed by one of the patients, without her memory she was living in a trance or

void, she was invisible like having lost her identity. Thus, memory constitutes an integral part of identity, which is a key aspect in dignity,

- *'I was isolated, didn't want to talk to anyone, because I had lost my memory... this affected my dignity...you understand?'* Mary

The outer appearance of the patient such as maintaining skin integrity with no wounds or scars, preserving the body intact without losing a body part, for example a breast, enhanced dignity. Clean clothes, normal hair, teeth, and facial shape were fundamental to self-esteem that boosts dignity particularly for women. Wearing a wig due to chemotherapy-induced alopecia was one of the most frustrating consequences of the treatment. Women tended to feel embarrassed, intimidated, unable to discuss hair loss openly with friends, coping with it with concealment and by wearing additional make-up on the face.

- *'Hmmm... I will tell you that for me the worst thing was my hair loss and the use of a wig. This was a topic that was very difficult for me to accept. Even when things were well, and I resumed going to work (as a teacher at school) that topic I couldn't talk about ... I was really touched by it and ashamed of'* Nelly

It is noteworthy that patients perceived chemotherapy and radiation sessions as usually painful experiences, both psychologically and physically. In particular, distress is high when the participant is obliged to expose intimate parts of the body like the breasts or the genital area during treatment. These cycles were loaded with emotions of loss of control, fear of the unknown, internal stigma and damage to dignity.

'I told him I have a session, he said fine, but why are you crying, I said I am scared. Scared... and finally my turn arrived and I went inside, I told her, Please doctor , may

God keep you, give me (tell me) something simple from your experience. She said, 'Ammo', nothing will happen to you. Then she said come in, and lay down and remove your underwear... yeh yeh What a scandal, I will remove my underwear?' Sam

Cancer was still regarded as '*the condition*', that is not talked about openly but is hidden away.

In this regard, gossiping, or discussions in the social circle about the sick person's health

condition, was regarded to be shameful and degrading to the dignity of the ill person.

Maintaining a dynamic reputation in the community was of utmost importance as this raised an

individual's worth as a valuable member in the society. In some communities, cancer was

regarded as a contagious ailment and highly stigmatised. This was clearly expressed by some

participants who perceived that society was discriminatory against individuals with advanced or

terminal illness. Another participant stated that upon her initial diagnosis her neighbours

avoided visiting her thinking her condition is infectious.

- *'... my neighbour who lives in the same floor, she stopped visiting me (very unhappy and annoyed), thinking that my condition is contagious, because she wanted to protect her daughter in law who was pregnant' Nelly*

An interviewee with blood cancer never mentioned the word "cancer" at all throughout the

interview but replaced it with the term "my condition". A young working, female participant

stated that she did not want pity from others but demanded equal treatment as a regular

human being with fair career opportunities. Pity from society elicited the patients' perception

of being weak, disempowered, and vulnerable. It reinforced segregation and consequently

demoralisation, resulting in hopelessness that did not resonate with dignity.

- *'Hmm...maybe...eh, when, for example, when you get sick, and people know that you are sick they start looking at you in a different way...eh...in a way that they pity you...eh. this is ...I think this is not right... eh... they start ...eh... labelling you. eh...which is ...eh... which in my opinion is very wrong.'* Lea

The stigma of illness was reflected in the reluctance of patients to visit the hospital as it was regarded as a 'dirty' or infected space that should be avoided. A participant expressed that he requested from his family to postpone or avert hospitalisation even if he is acutely ill in fear of contracting an infection that would further jeopardise his health and as a result affect his sense of dignity. Some described the pandemic as a 'disaster', a 'nightmare' or a 'ghost' that created national chaos.

- *'Yes, I was on my nerves "ana eaade aala aasabe", patients are coming and going ... I was so worried, my son becomes very worried for me, too since I cannot get the flu, I cannot get flu; it can directly affect my lungs and fill it with water'* Sara

The loss of dignity through the debilitating complications or effects of the treatments was very burdensome. Patients perceived that their dignity could only be restored by finding a cure or at least evading medical complications. This intense longing to find a cure or stop the progression of the illness was palpable in the participants, who actively sought frequent, multiple medical consultations from various health experts hoping to find a remedy.

- *Next, I went to another doctor... doctor (X) (they sound upset) ...because the other physician (doctor S) could not fix me, though I did everything he asked me to. Finally, after many consultations, the nose pimple dried up and fell off'* Ella

The diagnosis of the serious condition itself sometimes triggers an anticipatory grieving process of group mourning, characterised by family gatherings and hours of weeping and lamenting

over the destiny, or the upcoming gloomy fate, (death) of the ill individual. Family grieving is often a reaction to being aware of the closeness of death after the disclosure of the diagnosis. This family sorrow and group mourning, which is particular to Muslim oncology patients, affirms the communal perception that cancer is a life-limiting and incurable disease. It also indicates that most family members were aware of the patient's diagnosis. With this active grieving process, patients often experience psychological distress and anxiety 'turning the world upside down' when faced with the possibility of death and the unknown extent of suffering that awaited them.

- *'They (the brothers and sisters of the patient) were crying, sobbing, yelling... An hour of sobbing, nobody is talking to each other except crying, the only word you hear is Di3anak ya (what a tragic loss you are) 'Sam*

Some of the patients' fear of the unknown was overshadowed by their worry of how the family would manage their livelihoods after their death. This was observed to be true for men and women across the different religions and sects particularly, for those who would leave young children and spouse behind.

6.2.4 Theme 4: Compassionate & Comprehensive Care 'The physician kissed me on the forehead and told nothing is wrong with me'

Compassionate health services enhanced participants' experiences of dignity. In contrast, indifferent care demoted dignity. This theme also touches upon patient preferences and the impact of the socioeconomic and political state of the country on access to quality health services, that inevitably influences patient experiences of dignity. A kiss on the forehead in

Arabic cultures is associated with apology and comforting the kissed person acknowledging their grief (Ochuko, 2021). Health providers who approached patients with sensitivity and exhibited compassionate caring, providing direct attention and hope for better wellbeing, were regarded as resourceful, fostering patient dignity.

- *'The physician came to my room and asked about my wellbeing. I told him I had fever that day, he told me "come, come", he kissed me on the forehead and told me "nothing is wrong with you". He removed my leg stockings and told me to move my legs and start walking....' Nelly*

Participants desired to have respectful communication during their health service encounters where the physician is competent and takes enough time to assess, listen and then propose a treatment. Physicians who answer patients' phone calls, who are present and support the patient during chemotherapy or radiation sessions, who performed frequent ward rounds on their hospitalised patients, demonstrating an approachable and compassionate attitude throughout the illness trajectory, were regarded as ideal in fostering patient dignity. In contrast, physicians who remained distant from the patient in their posture or attitude, were volatile in their moods or non-empathetic in their responses or absent or passive during treatment sessions were not favoured. Kind and enduring communication that involves explaining and sharing information in a candid manner was appreciated.

- *'For me it is important that a doctor is always a good listener and listens to all questions ...This is what I want. These things comfort me. Sometimes they do not tell the truth the whole truth, though there are physicians who explain all the phases of the disease'*
Viviane

During the pandemic, hospitalised patients saw that nurses were overworked and at the same time not well protected or equipped to avoid contracting the infection due to a shortage of protective personal equipment and disinfectants. Participants explained how nurses performed shorter and less frequent hospital ward rounds to assess or check on their patients. The verbal and physical interaction between the patient and the health provider was compromised due to wearing masks that hid facial clues and sometimes resulted in miscommunication. Careful attention and individualised care were not always practiced by health providers, and this threatened patient dignity.

- *'Nurses were not always polite, so, because it is covid-19 time, the nurses stay in the room for minutes or seconds, she/ he does the work and disappears' Lea*

According to the patients, Covid-19 caused delays in providing prompt nursing attention to the patients such as answering the call bell or performing thorough and frequent assessment.

Though this was disliked as it affected quality of compassionate safe care, there was no active blaming made from patients to the health care staff, on the contrary, most patients sympathised with them believing they did their best to serve the sick in difficult circumstances to maintain their needs that enhanced dignity.

Information sharing was regarded to be an important aspect of care to the participants that enhanced dignity irrespective of language, gender, or age. One participant was skeptical about the superficial and non-convincing explanations of a physician when he asked about potential complications on his sexual health after receiving radiation therapy to the pelvis. Clear and simple information about side effects of treatment, chances of full recovery, a plan of care, was

of utmost importance to all patients to safeguard dignity. Communication about the type of surgery, or the identity of medical staff performing the procedure, resources to be secured prior to procedure (for instance units of blood), cost of the procedure, was information that was expected to be shared clearly by the health care providers to participants. One participant was very upset when she discovered after the surgery that one of the preplanned procedures was not performed during the operation. Hiding information was disappointing and diminishing to patient dignity. Parallel to open communication, proficiency in care through providing proper and effective management of symptoms was regarded as a crucial skill practised by the medical professionals in all encounters. Participants wanted trustworthy health care professionals who are capable of identifying and acting on the best possible treatment for the patient's wellbeing without hesitance or being affected by patients' socioeconomic variations.

- *'The thing is that they (health care providers) did not tell me that the insurance did not approve of the fees, and they didn't do the second surgery.'* Viviane
- *'The neuro professor couldn't regulate my high blood pressure, though I was sent to him by my primary physician'.* Elie

The participants had frequent interactions and encounters with the health care providers due to their progressive health condition. All participants actively sought Western state of the art medicine, perceiving it as the optimum method to restore their health and wellbeing. All interviewed patients preferred visiting physicians who were popular for their expertise in the community, practicing in private hospitals, regardless of their high charging fees. Health services or physicians educated in Western countries such as the United States were regarded of better caliber, knowledgeable, and respected for their proficiency and utilisation of high

technology. Western medicine was regarded as credible, trustworthy and the best means of restoring health and consequently dignity.

- *'I think high technology and quality care is found at the American institutions or hospitals; they were more polite. There is a different culture there'. Ella*
- *No no no. I never went to hospitals except the American, where the healthcare teams are... 'chapeau bas- French word (respectful)', really excellent'. Camal*

Participants expected that nurses, too, should share information and deliver compassionate care in health care institutions. Patients explained they liked nurses who took the time to sit with them and talked about their overall wellbeing, maintaining eye contact. In contrast, when nurses were merely performing responsibilities in a routine like fashion, they were regarded to be 'robotic', lacking attentive care and empathy towards the patient.

- *'...However, if the nurse talked to you kindly, it would make you feel better even if you were in pain, she would alleviate the pain'. Camal*

Another concern was about categorisation of the quality and the delivery of care in line with the ability of the patient to pay. Some procedures were performed by medical students instead of physicians on patients who were disadvantaged economically and could not pay directly from their pocket. The socioeconomic status or financial capacity of the patients and the power to afford services categorised them as privileged, or less advantaged to access quality and expert care. For instance, one of the health institutions catered for several types of clinic visits that varied with the amount of time allocated to the patient and consequently the charges of

the visit. Since most of the quality health care was privatised (The New Humanitarian, 2008), equal access of the poorer communities to quality health services was limited, creating inequity in health care and health status. This took a harsh toll on dignity.

- *'At this hospital, outpatient health care depends on time spent with the physician, sometimes physicians don't spend sufficient time with the patient, and this is not fair, and a very bad thing. If you have a long session, they charge a specific high fee, and if a short session they charge less'. Sara*

Specialised care that entailed just assessing one part of the body and denying broader assessment by the health care provider was interpreted by patients as fragmented care.

- *'But I don't care, I am a client, even if there are 50 more clients outside waiting for him (the physician) I have my rights and I need explanations and information. He said, "now you are coming for your nose, next time we check the other areas of your body" '. Ella*

Long waiting hours in the health clinics, or rushed quick encounters, were regarded as commercial, degrading of patient's dignity. One of the participants who did not have private health insurance or coverage explained how humiliated she felt, having to wait at the governmental organisation's door to secure a subsidy of the cost of her medicine. These occurrences were interpreted as diminishing to patient dignity and patient rights.

Individualised care that attended to patient needs and preferences, had a non-judgmental approach regardless of social class, acknowledged the psychological distress of the patient, and placed the patient's wellbeing as a priority was required to foster dignity.

- *'In Lebanon, it is not available, even the person who is insured, we stand in long queues "tawabeer" in front of the national security building to request our medications' Sara*

For many patients, the physicians who did not charge for the health consultation, were interpreted as noble and non-commercial. Participants often saw access to health care as a privilege for those who can afford it and not a universal human right. Quality health care was expensive and privatised, thus the chances of receiving basic health services were difficult for those with fewer finances, and this demeaned their dignity. Even the quality of nursing care provision in hospitals was sometimes influenced by the social status of the patient. For example, and those who could provide small gifts such as wealthy businessmen or popular clergy or politicians are regarded as the fortunate.

- *'If anyone belongs to a religious group, he is admitted to the hospital easily, Also, if you are a politician or something important, you will have no problem with the hospitals... it's a great deal'. Sara*

Some participants reported that the volume of diagnostic tests, the frequency of repeating tests for validation of results, and the multiple medications to be digested daily, were a heavy burden on the patients' social, psychological, and economic wellbeing diminishing dignity.

6.3 Summary

Four themes were developed that were the anchors of patient dignity: faith, family and children, overall wellbeing, and compassionate health care. Dignity, though potentially abstract, was cultivated and balanced within the personal, social, and environmental realms of the individual. The internalisation of religious beliefs and the supportive presence of family members comforted the individual by protecting dignity during serious illness. When utilising health services, compassionate patient-centred care that catered to patient needs,

characterised by kind attentiveness and ongoing communication was felt to be a crucial element to preserving patient dignity. Lack of uniformity in the standard of care to all social strata, the poor and the rich, was voiced unanimously. The next chapter presents the findings from the family caregiver interviews.

Chapter 7: Findings- Family Caregivers' Perspective

The findings from the family caregivers' interviews caring for patients with advanced chronic or terminal illnesses are presented in this chapter. Participants' characteristics are displayed in table 6.1. The four themes are a) Kind and loving discourse, b) Securing a good life, c) Maintaining the social role in the family hierarchy, and d) Compassionate health care. The four themes and their sub-themes are described below, supported with quotations from interviews with caregiver participants.

7.1 Participants

The 15 family caregivers interviewed were either spouses, sons, daughters, or close relatives living with or closely caring for patients in need of palliative care. The participants were actively involved in delivering direct hands-on care assisting in daily activities of living such as toileting and bathing. They also supported their relative in other ways, including paying for care or managing the patient's medical or health care needs, making appointments and accompanying them to the clinic.

All eligible candidates were recruited at random except for one family caregiver who was related and lived with a patient participant forming a dyad. The data were collected between September 2020 and April 2021. All recruits readily agreed to participate in the study once approached by the researcher. The interview time lasted an average of 30 minutes, ranging from ten minutes (stopped early due to connection interruptions in the phone line) to 49 minutes. Eight interviews were carried out via telephone calls because of compulsory governmental lockdown measures to reduce the risk of covid 19 transmission. The rest were

carried in person observing personal protective precautions such as social distancing and wearing a face mask.

The participants belonged to diverse sects and religions. Arabic, English, or Armenian language was used according to the participant’s mother tongue and preference. Most participant caregivers were females indicating the high involvement of women in the direct care of the sick at home. Many of the male caregivers were supporting the care financially, though some were hands-on caregivers. The participants lived in Beirut, except two who lived in the suburbs. Characteristics of the caregivers are illustrated in table 6.1. Pseudonyms were assigned to provide anonymity to the participants.

Table 7. 1 Participants’ Characteristics

<i>Pseudonym</i>	Interview method	Caregiver Relation	Medical condition of patient	Recruitment route
<i>C01 Zeina</i>	Telephone	Wife	Dementia and cancer	Outpatient clinic
<i>C02 Kawsar</i>	Telephone	Daughter	Stroke	Outpatient clinic
<i>C03 Muna</i>	In person	Wife	Hypertension, cardiac	Snowballing
<i>C04 Sima</i>	Telephone	Daughter	Cancer	Outpatient clinic
<i>C05 Remi</i>	In person	Daughter	Heart failure/ COPD ¹	Snowballing
<i>C06 Jean</i>	In person	Son	Heart failure/ COPD	Snowballing
<i>C07 Simon</i>	Telephone	Son	Heart disease/ HF ²	Snowballing

¹ COPD: Chronic Obstructive Pulmonary Disorder

² HF: Heart failure

<i>C08 Ibtihaj</i>	Telephone	Daughter	DM ³ , CAD ⁴ , PAD ⁵	Outpatient clinic
<i>C09 Thuraya</i>	In person	Daughter	Depression/ fibromyalgia	Snowballing
<i>C10 Husam</i>	In person	Husband	Diabetes, Alzheimer's	Snowballing
<i>C11 Ihsan</i>	Telephone	Daughter	Breast cancer mets ⁶	Outpatient
<i>C12 Saieed</i>	In person	Son	Thyroid cancer ⁷ mets.	Outpatient
<i>C13 Rana</i>	In person	Daughter	Lung cancer, head trauma	Outpatient
<i>C14 Salwa</i>	Telephone	Sister	Bladder cancer	Snowballing
<i>C15 Maya</i>	Telephone	Daughter	Alzheimer's, stroke, Diabetes	Snowballing

7.2 Themes

The analysis steps outlined by (Clarke & Braun, 2013a; Clarke & Braun, 2017) was applied identifying more than 200 codes across the transcripts (figure 6.1). After full immersion and engagement with the data, four themes and 13 sub-themes were developed (table 6.2).

³ DM: Diabetes Mellitus

⁴ CAD: Coronary Artery Disease

⁵ PAD: Peripheral Artery Disease

⁶ Ca: Cancer

⁷ Ca: Cancer

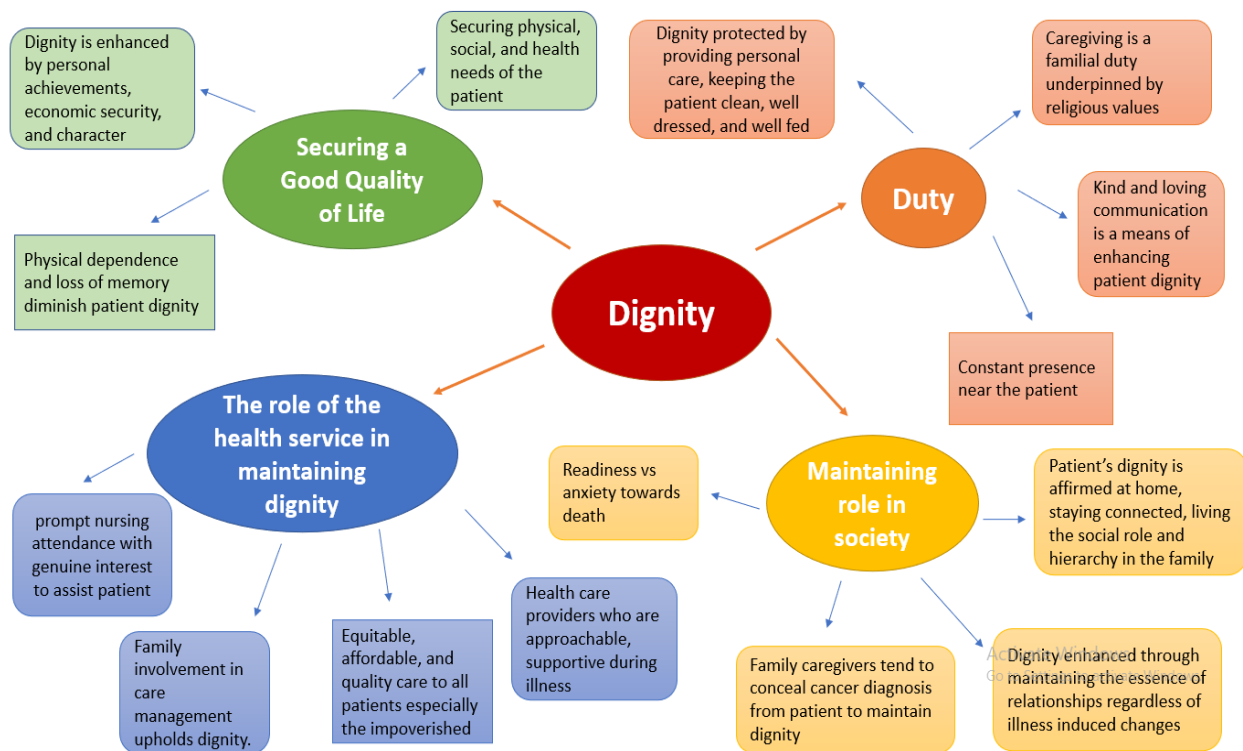


Figure 7. 1 Thematic mapping of the findings.

Dignity in the centre is supported by four themes: Duty, Securing a good quality of life, Maintaining role in society, The role of the health service in maintaining dignity. Each of the themes embraces the related sub-themes.

The first three themes unpack how family caregivers understand and protect the dignity of their ill family members within their homes or health institutions. The last theme elaborates how patient dignity may be enhanced or reduced in the hospital setting while receiving treatment.

Table 7. 2 Themes

Duty	<ul style="list-style-type: none">- Caregiving is a familial duty underpinned by religious values.- Dignity protected by providing personal care, keeping the patient clean, well dressed, and well fed.- Kind and loving communication is a means of enhancing patient dignity.- Constant presence near the patient.
Securing a Good Quality of Life	<ul style="list-style-type: none">- Securing physical, social, and health needs of the patient- Dignity is enhanced by personal achievements, economic security, and character.- Physical dependence and loss of memory diminish patient dignity.
Maintaining role in society	<ul style="list-style-type: none">- Patient's dignity is affirmed at home, staying connected, living the social role and hierarchy in the family.- Dignity enhanced through maintaining the essence of relationships regardless of illness induced changes.- Family caregivers tend to conceal cancer diagnosis from patient to maintain dignity.- Readiness vs anxiety towards death.
The role of the health service in maintaining dignity	<ul style="list-style-type: none">- Health care providers who are approachable and supportive during illness.- Prompt nursing attendance with genuine interest to assist patient.- Family involvement in care management upholds dignity.- Equitable, affordable, and quality care to all patients especially the impoverished.

7.2.1 Theme 1: Duty ‘Only kindness and sweetness are my duty towards him’

Family caregivers perceive caregiving as a familial duty and an inherent obligation through which they affirm their commitment to their religious beliefs and spiritual virtues. By adopting a kind and attentive relationship with the ill individual, family caregivers set the foundation for dignified care.

Caregiving is an intertwined journey of social exchange with the ill person where dignity and the wellbeing of the caregiver may be at risk for compromise in due time. Participants explained that taking care of a sick person is an emotionally, physically, and economically heavy

burden. However, preserving patient dignity is of utmost importance because good caregiving of the sick family member restores the family caregiver's reputation and honour in the community, upholding social status and respect.

- *'But I am doing this (caregiving) for God's sake and for my own honour. I must do this ... If someone came and saw his pyjamas and underwear dirty, his feet dirty, they would say, 'what is this woman? She doesn't take care of her husband'. Muna*
- *'Even when I face different ugly things with him, I accept it with an open heart because we are all susceptible to these things. ...So, if we as a couple, married for almost 60 years don't tolerate each other, so say farewell to God. Thank God, our relationship is based on respect, respect and affection'. Zeina*

Good care to their ill family member with palliative needs is regarded as a religious and filial duty. Family caregivers believe that taking care of the sick is a pious obligation and a responsibility that has a sacred or spiritual connotation, bringing the family caregiver closer to God and providing spiritual harmony. The family's understanding is that health, sickness and ageing are natural stages of life, controlled by God and need to be accepted gracefully. Taking care of the sick is like embarking on a compassionate journey, which is a moral act endeavoring to usher in spiritual peace or salvation. According to most caregivers, regardless of gender or religion, providing emotional and physical support to the sick nourishes self-esteem and cultivates spiritual wellbeing.

- *'As I accepted the sweet days, I must accept the bitter or the bad, because this can be the path to spiritual salvation from many things in our lives. So, I accept it'...So, preserving his dignity is by not using bad language, but only kindness and sweetness is my duty towards him'... Zeina*

For some family members, particularly those belonging to Islam, dignity is advanced through virtuous acts such as benevolent deeds, performing acts of compassion, serving the community voluntarily, feeding the hungry, respecting the elderly, and appreciating people from diverse backgrounds. Thus, family caregivers stay vigilant and careful when providing compassionate care and kind communication and ensure there is no shouting or use of harsh language. Their spiritual conviction helps them to maintain the general wellbeing and dignity of their family.

- *'The most important thing is making her feel love and kindness. It is important to let her feel that I care for her, and I love her, and no matter what she does or happens I will always accept it.'* Rana

Family members enhance patient dignity by providing support to the sick member through maintaining personal body hygiene, clean clothing, securing the medications and daily meals. According to the family participants, caregiving is an intricate and challenging responsibility that involves disciplining the self to stay kind, accepting, enduring, and being in a 'giving' mode with the patient. Caregiving may involve intense emotions such as personal deprivation, feelings of loss, and unwavering commitment to continually uphold patient dignity and maintain care. Family caregivers who could not afford to have formally paid caregivers to assist them in cooking, cleaning, or patient care, were more burdened than others who had that privilege. Though fatigued and sometimes in distress, family caregivers felt obliged to provide daily care staying faithful to religious beliefs and avoiding disgrace in the community.

- *'she's very good, living dignified, everything is cleaned, she has everything she needs. Her food, and everything...'* Salwa

Family caregivers spent days and nights with their hospitalised mother or spouse, depriving themselves from personal care, such as sleep. When patients are hospitalised, family members are always present with the patient to provide support and safeguard patient wellness.

- *'Now when my father was hospitalised recently, I stayed with him most of the time, I never leave him' Remi*
- *'Yes, I sleep beside her, and I keep on taking care of her day and night. (her voice suddenly became sad, and she started crying) ... she is my mom...'* Ihsan

Taking care of the sick member is a collective family responsibility exhibited by the division of tasks and responsibilities of care amongst each other.

- *'So, since my aunt is now passing through this hard situation, so... we need to be by her side. "Ma feena nofrot kelna", we can't be weak or divided, she is passing through a tough period, and we have to help her.'* Ihsan

Most of the married caregivers who were taking care of their spouses stated that their sense of dignity has merged and united with that of their partner. So, their individual dignity is inevitably enhanced or damaged through the dignity of their ill spouse. For instance, a wife explained that she feels happy when her husband is nicely dressed, or when he is washed clean because his wellness reflects on her own wellbeing and morale. Physical cleanliness of the patient's body and neat appearance had a vital significance on preserving dignity for most of the female family caregivers.

Soothing communication, maintaining respect, a clean body, securing nutritious meals and medicines (which were in short supply in Beirut) were regarded as the basis for a dignified life

for the ill individual with palliative needs. Active listening, constant presence with the sick, respecting individual preferences, and accepting patient weaknesses with an open empathy were considered important aspects of dignified care.

7.2.2 Theme 2: Securing a good quality of life ‘Make sure all patient’s needs are met’

Family caregivers all expressed the feeling that dignity of patients with advanced and terminal illness is maintained through a good quality life where physical, psychological and health needs are met. Family caregivers are ready to attend to the needs and dignity of the patient from providing basic physical support to social entertainment, symptom management, personal space, supplies, and health care services. All the participants wanted to see their sick family members content, calm at home, comfortable and without pain.

- *‘Of course, of course. My mother’s dignity is a priority to me, that she doesn’t feel upset. I make sure that all her needs are met, that she has nothing to complain about.’ Maya*

- *‘We are talking about securing his own medication, his own income that will ensure a good quality of life especially at old age’ Ibtihaj*

All family caregivers expressed that life experiences and accomplishments build endurance, dignity, and resilience. Achievements such as gaining higher education, success in a career, perfecting a talent, living by principles in life, having a good reputation at work all enhance pride and dignity. Family caregivers understand that achievements are vital to maintain a respectful socioeconomic status, sustaining the livelihood and the dignity of the family by improving their quality of life or meeting their needs. This notion was elaborated by a male caregiver who stated that dignity entails having ‘broad shoulders’, associated with being a

reliable person, capable of bearing responsibility, enjoying economic independence, loyal to friends and family and respected in the community.

- *'Dignity is about ... what you have learned from your parents, school, and college, you know... strength in character and self-esteem. Perhaps having broad shoulders.... I support myself. I rely on myself'. Simon*

A dignified status in society is accredited by living a good quality life, occupying a well-regarded formal position, accumulated wealth, seniority in a rank, and living a content life. Family caregivers explain that economic prosperity and entitlement allows power and capacity, even in religious communities such as churches, imposing respect, and bolstering dignity.

- *'... I'm in the board of directors, whenever we have a ceremony or a gathering ...hm.... they always say sit here or there, ushering me... there's my name written on the chair... may be this dignifies me, ... being there as part of a community is important' Jean*
- *'Someone who is well off is respected more. But that is the fake respect, because he has got money we should respect him, that is what happens.... and we can see that in our society' Husam*
- *Though most participants state that money brings social power along with dignity when palliative care patients lose physical power and affluence due to the prolonged and intense illness, their value and "genuine dignity" is preserved through the individual's character, and previous life deeds regardless of health or power status. So, when physical or financial wellbeing is lost dignity is still maintained through legacy and virtues.*

Asking for monetary assistance diminishes dignity and may even lead to social isolation. Thus, requesting services or help from others is not desirable as it implies weakness and inadequacy.

Poverty, and thus being unable to attain a good quality of life, quality food, respectful health services and essential medicine are indicators of deficiencies that do not resonate with dignity as needs cannot be met.

- *'Don't ask for monetary assistance from anyone. If you ask for assistance people will run away from you and gossip ...they will isolate you, and not relate to you'. Muna*

According to the participants, even asking for physical assistance, for instance, using a cane or calling someone to assist in ambulating or toileting, is humiliating to the patient. For this reason, family members offer help proactively to the patient to reduce the feeling of incompetence or ask for approval before offering support.

Some participants explained how they occasionally find themselves in a dilemma while providing support at home to the sick family member in their daily activities. A daughter explained that she asks her mother for permission to complete home cleaning tasks, as her mother, who suffers from chronic fibromyalgia and depression, could feel her dignity and mood is compromised if she is unable to perform her responsibilities routinely without needing help. Lacking the physical power to take care of self and the daily errands made patients feel useless and undignified. Thus, family caregivers ensured that patients were willing to accept their offer of assistance before initiating various activities, such as changing clothes or giving a body bath.

- *'I tell her that, I just want to help and see if she wants, she accepts my help. I ask her first "can I do this?" "Let me help you with this." "Do you want somebody to be with you?" Thuraya*
- *'When she can't reach the toilet in time, this affects her badly'...Husam*

Families recognised the patient's embarrassment and loss of dignity if they suffered from incontinence, and how the loss of control affected the way patients viewed themselves. Family caregivers are also eager to maintain the cognitive awareness and mental capacity of the patients by directly orienting them to time and place. States of confusion and memory loss do not encourage dignity.

- *'so, sometimes they look down upon these patients, or they joke around with them, I know this can happen, making jokes of people who are not fully aware'* Husam
- *'I was mostly upset because of her memory loss, in the beginning she thought we were in a different hospital and in a different country, then she started remembering with time. She mostly remembers the old memories, events. The new experiences or events are frequently forgotten. I try to keep her dignity high at all times ...'* Husam

Though loss of dignity is not directly related to sickness, the participants envisioned dignity could be maintained in pleasant circumstances, with no burden of physical symptoms, where the ill individual is financially comfortable, with acceptable physical functionality and cognition. Socioeconomic sustenance is by default a core factor in keeping the dignity of the patient and the family in meeting their needs.

In times of drastic economic crisis and shortage of essential goods, as in the current status quo in Lebanon, the dignity of individuals with palliative needs is at threat. Patients and families are vulnerable and in distress, which does not resonate with dignity and having 'broad shoulders'. During the pandemic one of the family caregivers explained how his father lost his dignity due to a shortage of oxygen.

- 'One time he was begging for oxygen... so I think he felt bad, hmmm because of the illness of course and the scarcity of resources. So yes, the illness, the pain, the shortness of breath, hm shake his dignity' Jean

7.2.3 Theme 3: Maintaining the role in society 'My father is still the caretaker of the family'

Family care givers illustrated how patient dignity is shaped and maintained within the individual's community network, social role, and hierarchy among family. Dignity does not exist alone in an absolute state but is deeply seated within the collective societal values and connectedness that construct the contextual meaning of dignity. Family caregivers believe that dignity is understood and practiced in reciprocity, for example, in daily communications and encounters irrespective of differences in age, religion, or gender. Family caregivers explain that dignity and a meaningful life is enjoyed when one is among a close circle of friends or family. Identity and dignity have meaning when an individual is amongst acquaintances sharing personal stories, experiences, laughing together, or disclosing interests, secrets, or dreams. It is in this communicative network and social capital that an individual establishes dignity. For this reason, patients are kept at home and within their family roles until their health deteriorates drastically and hospitalisation is urgent. In this regard, placing the ill person or the elderly in a nursing home is not favoured as this may be interpreted as insufficient care or a selfish act from the family members.

A male caregiver explained that he boosts his mother's dignity through frequent visits, friendly chats, jokes, affirming her role as a mother by stating that her cooking is the best. The need for confirmation of the social role of the patient in the family hierarchy as a father, a mother,

housewife, or a partner and acknowledgment of its value was often practiced preserving patient dignity by the family caregivers throughout the data.

- *'She needs to be pampered, she needs to laugh, she needs rest, she always needs phone calls if I am not around. If I am around, I pass by for a cup of coffee, or take her for a ride in my car you know, these things will make her always happy' Simon*
- *'For me, his dignity is above all dignity, so that he stays as he was before, productive, father of his children, and a giving human being, so his role is not finished in his life' Zeina*

According to the participants, during the illness, the patient often undergoes changes in character, sometimes becoming more childish, demanding, and impatient, affecting the nature of the relationship between the patient and caregiver. A daughter regretfully said that she doesn't have a mother-daughter relationship anymore, but instead, *she* is acting as the mother. Family caregivers overcome this situation with humor, gentle communication, and acknowledgment of the individual's social role maintaining the essence of the relationship, the role and dignity of the patient.

- *'He is still the caretaker and the head of the family; he says to us "do this ... do that" he wants to be in control of us that makes him feel better. and this is true for my father and my mother' Ibtihaj*

Caregivers regarded their ill patient as vulnerable and defenseless. They felt that to tell their relative the truth of being close to death would be devastating to their wellbeing. Thus, some caregivers avoided disclosing the diagnosis or prognosis to the ill person, and instead used euphemistic terms to explain the condition such as an *infection or growth of a 'lump'* to replace

the term cancer. According to some caregivers, death is unwelcomed, and talking openly about it might bring evil upon the family. Some of the family members, who were aware of the diagnosis, suffered alone in silence as they took in the bad news themselves without having the chance to share their sorrow or grievances with others. Sometimes they shared the truth with limited family members to avoid the spread of the news in the community and subsequently protected the dignity of the patient through concealment.

- *'I won't tell her (patient) about the metastasis... I will tell her that there is some residual 'lump' showing from the old thyroid ... I will tell her but not everything at once.... Early morning, I was down at the pier crying...I don't want the news to be spread. I don't want the news to be spread'. Sabah*

However, caregivers of patients with non-cancer conditions, and those patients who were more fulfilled from their life experiences, or felt secure in their accomplishments experienced a sense of preparedness towards their death, enjoying inner satisfaction and peace.

- *'I provided good upbringing and education to my children, saw them get married, we had our journeys, and If there is going to be death (God forbid) I am ready for this decision. Of course, this is the decision of God, not that we do it, so I have accepted all these topics with full positivity, and don't feel it awkward' Zeina*

Since dignity is cherished in social circles, it needs to be protected and preserved from community gossip. Since cancer is still a stigmatised condition in Lebanon, it is associated with negative discourse and misperceptions of incurability (Bou Khalil, 2013). In this regard, discussions about an individual's deteriorating health are regarded as shameful, and damaging to a patient's dignity. Some aspects of the data reveal that in a closely knit community, where

people are engaged in each other's affairs, dignity is preserved through maintaining secrecy. Thus, though collective connectedness enhance dignity and provide a sense of security to the patient, private or personal boundaries are guarded carefully, to prevent any violation that may occur through inappropriate inquisitiveness by other social groups.

7.2.4 Theme 4: The role of the health service in maintaining dignity 'The approach of nurses was more than giving meds'

This theme illustrates features of health care institutions and care provision methods that enhance or diminish patient dignity, from the perspective of the family caregivers. Physicians and nurses were the only members from the health care team mentioned by the participants. Sometimes 'mediators or personal contacts'- 'wasayet' were revealed to be essential human links or acquaintances to ensure patient access to quality health institutions or services. For instance, those who were not connected to a political party or an influential leader, suffered from delayed hospital admissions or had no admissions at all. Political acquaintances hugely facilitate or hinder hospital admission process.

Family caregivers sought out physicians or nurses who were engaged and interested in genuinely addressing patient needs and assisting them. A physician or a nurse who is approachable, accepting the patient regardless of ethnicity or social rank was regarded to be noble because this attitude fostered patient dignity. Caregivers were upset when hospital nurses were absent for long hours or did not answer call bells promptly, necessitating family members to take over some of the nursing care, such as assisting the patient in the toileting or feeding. Such delays in care damaged patient dignity. Eating well and having a good appetite was regarded to be a sign of good health. Thus, caregivers were concerned when nurses did not pay attention to patient appetite or daily feeding.

- *'the approach of the nurses to my mother was humane, compassionate, more than just giving the medicine- 'take the drug'. In the other hospital, it was only medical and technical care.'* Remi

Participants expected health care providers to show understanding and empathy towards the patient's weaknesses, and to have attempted various alternative measures to improve conditions before resorting to artificial or invasive measures. Imposing an intervention on the patient such as applying hand restraints to an acutely confused patient, or insertion of nasal feeding tubes without attempting alternative methods of feeding, or negotiation with the family, was regarded as violating patient freedom and subsequently dignity.

- *'The doctor told me we want to insert a tube from her nose for her feeding, because she is not eating (upset), but a friend, told me that I can get a syringe instead and put the smashed food inside it, and then I can feed her like that. I did that and it worked. I am grateful for her'* Maya
- *'It was unnecessary (the restraints). We could have resolved it if they had called us, and that made it worse for her'. Thuraya*

Family caregivers valued health care providers who communicated kindly with the patient and family, explaining the plan of care or future expectations in simple words, showing support. In contrast, communication that was limited to merely medical details or prescriptions, without addressing the psychological and social needs of the patient, was regarded to be too technical and unsatisfactory. Blaming the family members for a medical complication or a delay, responding impolitely to queries coming from the family, poor or delayed provision of care due

to limited or no coordination among health care team members were viewed as robotic, disappointing, and undignified to family caregivers as well as patients.

- *'The good thing is the cardiologist was supportive...He assured him ...that the stents would last and that if he is compliant with the medication and he controls his blood pressure he would be fine so his explanations were very supportive of my father, and he would continue his normal life activities. The whole health care team all of them were very supportive, professional with plenty of explanations for him' Ibtihaj*
- *'At 4 o'clock in the afternoon I (daughter of a sick patient) somehow managed to get the phone number of the physician and I called him. He got mad. And he started saying "why are you calling me, the day hasn't ended yet!". I was calling him because he hadn't visited my mom and we wanted to know the plan of care (upset) ' Thuraya*

Some family caregivers demanded that health care providers, particularly those who would visit the patient for teaching-learning purposes with their medical students, ask for patient consent. They requested a clear and detailed explanation without medical jargon. Medical terminologies increased the power gap with the patient reducing patient dignity.

- *When doctors don't say everything about the case or use language we don't understand, as if he has more power, this is bad'. Sima*

Family members were constantly present near the sick individual when hospitalised as this was a cultural norm and indicated caring for and dignifying the patient. Family members expected the physician to review the medical plan of their relatives often and share the plan of management with them because they were closely involved in the care. A female caregiver stated, with laughter and irony, that the hospital guards thought she was one of the working staff due to her frequent presence.

- *'My mother had cancer for six years and she stayed in the hospital very long. Then, two months after her death, when I came again to the hospital the guard asked me if I had left my job in the hospital, thinking I am a staff'. Rana*
- *'A lot of times you would need the doctor but cannot find him, they would tell you he assigned another person, a resident, even at high class hospitals, the physician might have left for a weekend, they would tell you "we are in contact with the physician and telling him everything", but the patient will always want to hear from the doctor himself/herself. Because no matter what, I employed you to come tell me, not for you to assign others to come and tell me what's happening'. Sima*

Family caregivers preferred nurses or physicians who used gentle humour in their encounters, conversed with the patient using encouraging and amiable language, and who empowered the family members, as they were perceived to uplift patient dignity.

- *'So, my father needed to walk. One time, two nurses came in and started joking with my father. They said let's go have some fun, let's have a walk around, and they took him by his hand, for a stroll and then brought him back... hmmm... and he was doing it with a smiling face. Yep.. I think they really cared about him, and they were very cautious that he doesn't get angry or upset and feel safe with them.' Jean*

On the other hand, prescriptive language that holds no space for negotiation, and prescriptions of multiple medications were not welcomed, especially from male patients who tend to refuse to abide by instructions. According to the caregivers, female patients were more willing to follow medical instructions, accepted physician guidance and showed more compliance.

Labelling the patient as non-compliers to prescriptions reduced patient dignity.

- *'Look sometimes my father has very poor compliance in his diabetic journey, when his physician gave him various instructions and comments about his lifestyle, inferring*

that he (my father) is not compliant and that he should do something about it eh... he got annoyed of it, he didn't accept, and it felt offensive to him.' Ibtihaj

The rushed encounters between patient or family and health care provider, or when health care providers ordered daily diagnostic tests and charged additional fees, were regarded as commercial, improper, and damaging to patient dignity. Though many family caregivers had smooth admissions to health services and were grateful for the care they had received in health institutions, this was not the case for all participants. Some family caregivers revealed that some physicians do not offer regular follow ups for hospitalised patients who are not affluent or who hold an important rank. Thus, health care provision was not uniform with all patients but varied according to their socioeconomic status or political affiliation. For instance, larger rooms, abundance of basic supplies (such as water bottles), and frequent physician follow-ups were the norm for the wealthy patients, which maintained their dignity, but this was not always the case for underprivileged patients.

- *'Doctors should give equal time to everybody, not that because X person works in a famous company, they give him more time and talk to him leisurely, on the other hand they pass by quickly on a patient who is poor or from low class'. Sima*

Some participants explained that not having enough money to pay for the hospital expenses was one of the most humiliating experiences.

- *'Last time, my daughter told me I paid the bill of the hospital, but they called me again asking for another payment. I told them my daughter had 'closed', paid the bill and paid all our dues, they told me no, you need to pay for the exit charge and the cost of the documents we used. I didn't have the amount, I had only ..., this is my*

day's money (for daily living), I told them if you accept take it or else keep the patient with you. This is the worst thing that has ever happened (angry)' Muna

The financial strain has been much worse for Lebanese patients and their families in the past few years due to the Covid-19 pandemic, immense economic depression, shortage of resources, and the financial crisis. Patients' purchasing power for healthcare has been jeopardised by high inflation and the devaluation of the Lebanese currency. This situation has resulted in higher health care costs, which is painful for patients (Isma'eel et al., 2020).

- *My sister is well off, but we had several million liras extra pay as 'uncovered items' by our health insurance in the bill. In the emergency room, they took the same scan three times; they even billed the water bottles. It's overpriced.'* Salwa

7.4 Summary

The family caregivers felt that patient dignity is preserved through kindness, being attentive to the patient's needs, and ensuring cleanliness, hygiene, food, a comfortable home and medicines. The patient's dignity is also preserved by a commitment to keep them in the family social hierarchy and in contact with their circle of friends. There is a reliance on this social connectedness as a source of nurturing patient wellness, which enhances dignity. Adequate finances are vital to sustain the patient's quality of life and to ensure at least the minimum of basic health care in an expensive health care system. However, when material wealth or physical fitness is lost, family caregivers also regard good character and values as genuine constituents of dignity. Patients want to keep their physical function and independence, thus, family caregivers aim to provide as much space and opportunity for independence as the patient's condition allows.

Family caregivers commend health care providers who are approachable, caring, attentive and vigilant in their care because this improves patient dignity. Giving clear information that is simple and understandable is praised. Family caregivers are highly involved in the provision and management of patient care. They call for equitable health services, where patients of all socioeconomic rank and class have access to the minimum of quality health care and services, and in this way dignity is maintained.

In the next chapter the findings from patients and family caregivers will be compared, and then discussed in relation to the wider literature and model of dignity.

Chapter 8- Discussion

8.1 Introduction

The key themes provide a unique insight into the concept of dignity in patients and family caregivers with palliative care needs in Lebanon. Research in palliative care is scant in Lebanon, and in particular on dignity during illness. Hence this study is pertinent in understanding this concept from patients' and family caregivers' perspectives. Upholding dignity is one of the expected patient outcomes during illness in palliative care (Chochinov et al., 2002b), and a core ethical value in medical and nursing practice in delivering quality health services (Code of Medical Ethics. 2012; International Council of Nurses, 2021; Nursing Midwifery Council, 2015; World Medical Association, 2018). The research findings demonstrate an understanding of dignity and its multiple facets from the viewpoint of participants from an Eastern Mediterranean country and how it is preserved (or not) during illness. It reveals that dignity is intertwined with preserving a personal relationship with God, upheld through being loyal to religious values and virtues in life. Patient dignity is maintained through the support and active presence of the family during the illness experience who embrace the patient with care which is underpinned by familial duty to sustain the patient physically, emotionally, and economically. Physical and mental functionality are important elements that enhance patient dignity and connectedness within the society. The availability and affordability of quality health services that cater to all patients equitably without discrimination is vital to maintaining dignity. In this regard, medical and nursing interventions that are attentive to patient needs and preferences, are kind, respectful, compassionate, equally provided to all patients, and are informative of the patient condition, are aspects of dignified care.

These findings reveal the importance of the availability of resources and quality personnel, the importance of having economic sustainability, the geographical and societal nuances, uncovering culturally sensitive actions that could improve and conserve patients' experience of dignity.

Values vary across nations and following Inglehart et al. (2014) in their definitions of world values Lebanon is defined as a 'traditional country' placing emphasis on survival through physical fitness and economic security (Intglehart et at, 2020). Traditional countries emphasise the centrality of God and a superior control of life events, family values, close parent-child relationship, and obedience to authority. Secular countries favour contrasting values such as individual agency, independence, gender equality, with less emphasis on religion. There is more acceptance of divorce, homosexuality, and euthanasia (Intglehart et at, 2020). The cultural map by Inglehart and Welzel (2005) demonstrates that as societies go up the y-axis, they move away from traditional beliefs to become a more secular society (Refer to Figure 7.1). As countries move to the right on the x-axis, survival needs are replaced with that of self-expression, where there is more focus on subjective wellbeing, quality of life, environmental activism, and the right for participation in decision making in political life. Lebanon's position on values leans towards those of traditional and survival, reflecting the dominance of religion as a major ground for support, reinforced with close family ties. The sense of dignity is deeply dependent on maintaining physical function and economic sustenance.

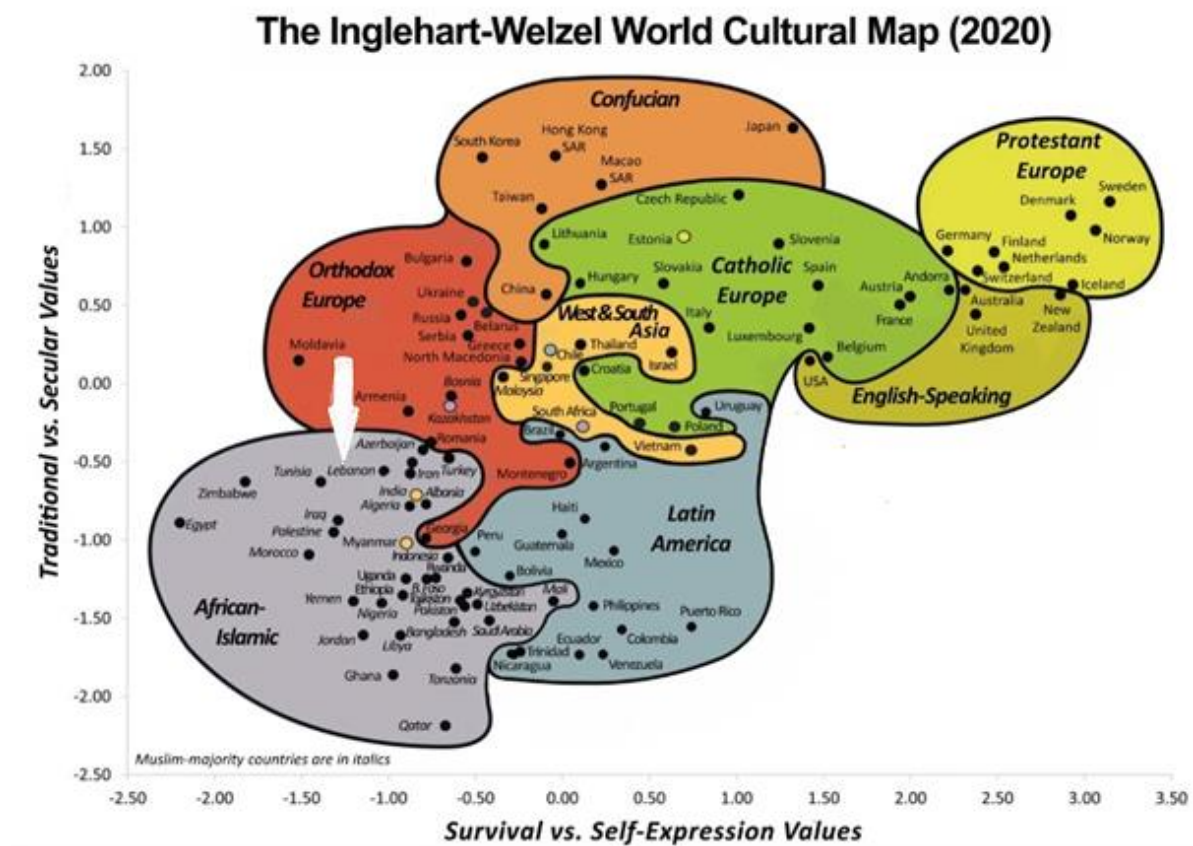


Figure 8. 1 Position of the Lebanon adapted from the Inglehart-Welzel World Cultural Map - World Values Survey (2020)

8.2 Summary of the findings

The findings underscore that a patient’s sense of dignity in the Lebanese context is multifaceted, influenced at both the individual level, but also through familial, communal, societal, broader environmental and socio-political factors (Jacobson, 2009; Kadivar et al., 2018; Pleschberger, 2007). On the one hand, dignity is maintained through the physical, mental, and social wellbeing of the individual, where the patient enjoys basic needs for a decent life such as a home, family, food, and medicine, all reinforced with an agreeable connection with the Creator and within their community. On the other hand, patient dignity, though personal, can only thrive in a macro environment that can cater to the essential survival needs of the patient

and secure a quality of life in illness. Having access to the health care system, with effective medical and nursing services that cater to all patients equitably to relieve illness-related suffering, regardless of social or economic status, is a vital requirement for dignity. Patients feel valued when they receive respectful, kind, and vigilant health services concordant to their personal values and preferences (Bagherian et al., 2019; Ho et al., 2013)

The analysis from the patients' interviews reveal that dignity is interpreted as a core human need preserved through a) maintaining spiritual faith and trust in God's omnipotence, b) obtaining support from family or friends, c) sustaining physical, social, and mental wellbeing and d) receiving compassionate care services. The data from family caregivers produced four corresponding themes that promote patient dignity. The themes were a) duty to provide kind and loving care to the patient b) securing a good life for the patient through obtaining essential needs c) preserving the patient's social role in the family hierarchy d) receiving compassionate, affordable, and equitable health care services where the family is involved in the medical decision making.

First, a comparison of the findings from the patients' and the family caregivers' perspectives is explored. The themes are also compared with the existing literature from the integrative review (see Chapter 2) on patient dignity in the Middle Eastern setting (Dakessian Sillian et al., 2021).

In the second part of the discussion, the findings are assessed for congruence against the Chochinov Model of Dignity (Chochinov et al., 2002a).

8.3 Comparing the patients' & family caregivers' perspectives on dignity

The findings from the two groups showed commonalities even though participants were not related, except for one couple who were married. Though the Chochinov Model of Dignity (

Chochinov, 2002) was identified in the literature as an established concept in patient dignity with palliative care needs, the analysis of the interviews in this study was inductive and the themes were developed from the raw contextual data (Thomas, 2006).

8.3.1 The Similar themes

8.3.1.1 Faith

For patients and family caregivers the concept of dignity is elusive and fluid. This makes it difficult to articulate or define, as noted by other authors (Enes, 2003b; Franco et al., 2019 ; Griffin-Heslin, 2005). Nonetheless, dignity is found to be of great importance to both patients and family caregivers (Manookian et al., 2014) who understand it as an inherent feature related to personal character, individuality, and virtue (Manookian et al., 2013). Patients perceived illness as a natural event that could arise in any individual's life, as it is sent from God and not something that can inherently change their sense of dignity. However, poor care was described by both caregivers and patients to adversely affect dignity. For both groups then, dignity was perceived as an inherent feature that should be protected regardless of the health status.

Patients and family caregivers found divine faith, prayers, and religious communities supported dignity and wellbeing, providing hope in challenging times of illness or during the heavy responsibility of caregiving. Family caregivers took on the responsibility of providing total care, maintaining a kind and loving discourse, despite the burdensome caregiving journey to invoke peace of mind and acquire religious comfort. Similar to other cultures, such as Eastern or Asian, Lebanese caregivers took charge of the care of the sick or old family member, as this was perceived as a pious and familial duty (Chan et al., 2012; Lai & Surood, 2009; Pan et al., 2022) arising from religious teachings that gave meaning and purpose to their life and relationships.

Spirituality and keeping personal faith were the main coping mechanisms that generated dignity for both patients and family caregivers, together with a feeling of being settled, having hope and a degree of certainty in troubled times. This finding is common in different communities worldwide (Egan et al., 2016). For instance, South American and Latino family caregivers employ spirituality and prayers to relieve the emotional burden of the caregiving (da Silva et al., 2018; Vigna et al., 2020). Reliance on the healing power of the Divine to transcend the immediate physical suffering for patients with terminal illness and inspire hope for a better life, is a ritual in multiple ethnic groups in the U.S., Korea, Middle East, Europe, New Zealand, and Puerto Rican (Dakessian Sallian et al., 2021; Egan et al., 2016; El Nawawi et al., 2012; Gijssberts et al., 2019; López-Sierra & Rodríguez-Sánchez, 2015; Yoon et al., 2018).

The participants, similar to South American patients in palliative care, associated dignity with morality and integrity expressed through living an honorable life (Franco et al., 2019). Acts of charity such as helping the needy or the weak were a means to secure dignity, reputation, and status in society. Associating dignity with morality and leading an honorable life resonates with both Western and Eastern philosophies (Schroeder & Bani-Sadr, 2017). It echoes with the Kantian assumption that dignity is an integral human attribute engendered by God, revealed through human decency and goodness (Balabanov, 2019; Hernandez, 2015; Kant, 1981). In the Middle Eastern setting, dignity is also associated with integrity and nobility, albeit reflecting the existing sociocultural and religious context, which advocates equality and a justice-based approach among human beings (Kadivar et al., 2018; Schroeder & Bani-Sadr, 2017).

8.3.1.2 Physical, mental, and social wellbeing

Both participant groups agreed that physical function affects dignity and morale, as control over daily routines and normalcy are lost if illness diminishes physical ability. Being able to carry out daily activities independently is associated with a positive sense of dignity in palliative care patients in North America, Northern and Southern Europe, the Middle East, as well as Asia (Chochinov, 2002; Dakessian Sallian et al., 2021; Enes, 2003a; A. Ho et al., 2013; Ostlund et al., 2012; A. Rodríguez-Prat et al., 2016). For this reason, family caregivers were cautious about respecting the physical independence and personal space of the patient whenever the patient was well enough to do everyday tasks.

Lebanese culture places a high value on the outer appearance and physical fitness of a person and an individual is often judged by merely assessing the look of their hair, face, body shape, or clothes (Chahine, 2003). Thus, any change that indicates a fading of former physical appearance or vitality, especially in female patients, such as losing their hair, or a breast, or wearing a wig, is a threat to dignified social interactions. This need for an impeccable look can be explained through the gendered role of women where outer beauty is a praised attribute (Hamieh & Usta, 2011). Physical fitness is a predominant factor in women asserting their role and agency during illness (Avis, 2017; Usta et al., 2015).

The findings reveal that cancer, and its traditional treatment modalities, such as chemotherapy or radiation, are associated with personal stigma in both men and women. The stigma of cancer or the debilitating effects of treatment on the body spark distress as displaying physical changes diminishes dignity and quality of life (Almigbal et al., 2019; Ernst et al., 2017; Gogou et al., 2015). Cancer carries a sense of shame, fear of fatality, and cultural myths that push patients

and family caregivers to remain silent about the medical condition, concealing it from their social group and bearing the emotional burden alone (Daher, 2012). Stigmatisation of cancer has been associated with social isolation, self-blame, and depression in various cultures in African and Asian countries (Ernst et al., 2017; Kang et al., 2020; Oystacher et al., 2018b; Phelan et al., 2013). Comparable to Asian, South African, and other Middle Eastern families, family caregivers resorted to withholding the diagnosis from the patient with the intent of preserving positive morals, self-esteem, that is a core aspect of dignity (Dakessian Sillian et al., 2021; A. Ghoshal et al., 2019; Oystacher et al., 2018a). Negative stereotyping of cancer also exists in some European population subgroups presenting a barrier to cancer screening (Vrinten et al., 2019), or receiving psychological support (Schuit et al., 2021). The burden of stigma is so high that studies show Lebanese patients avoid the use of the term cancer as this may risk their relationship with family and friends, their wellbeing, and consequently their sense of dignity (Knapp et al., 2014; Stolberg, 2014).

Family caregivers and patients stated that loss of memory or low mental acuity diminished dignity too as it led individuals to becoming socially isolated and invisible, limiting their ability to communicate or voice their concerns. Poor mental awareness or dementia have been reported in European studies to weaken personal autonomy and agency, creating challenges in provision of daily care and particularly in older adults in maintaining their dignity (Rejnö et al., 2019; van Gennip et al., 2016).

Findings clearly revealed that to maintain communal support, respect, and consequently dignity, patients yearned to preserve their outer physical and mental fitness, whereas family members longed to maintain a good social reputation by taking on the responsibility of

caregiving. The need to escape community 'gossip' was a common observation in both groups of participants, similar to Moroccan and Turkish patients with palliative needs (de Graaff et al., 2010).

8.3.1.3 Family presence and support

Not only is dignity nurtured through keeping a personal connection with the divine, or by feeling physically fit, but it is also secured through social connections, having children and family support (Ho et al., 2013; Xiao et al., 2021). It is noteworthy that most family caregivers were female, younger than the patient and lived in the same household. These attributes are typical to low-income countries indicating gendered roles of caring for the sick (Abdel-Malek et al., 2019). Family members, similar to African societies, assumed and led the caring responsibilities through active involvement in direct or indirect daily tasks such as bathing and dressing the patient, or ensuring there is a plan of care (Salifu et al., 2020). Family caregiving is a common social norm in Asia, Africa, and the Middle East families where the supportive role of the family members in meeting the needs of patients with palliative needs is profound (Adejoh et al., 2020; S. Dakessian Sallian et al., 2021; Tan-Ho et al., 2020). Patients perceived family and children as the means through which their own dignity, personal legacy, and secure social connections are guaranteed. Family and children enhanced a patient's dignity as they provided the safe space for healing and being valued despite their vulnerability (Ho et al., 2013).

Family members crafted the essential survival net catering for the physical, nutritional, hygienic, and emotional needs of patients keeping them well cared for, socially connected, and dignified. Children, spouses, and friends offered psychological and financial support validating the social role of the individual in the family hierarchy, maintaining a frequent presence, and

keeping up visits that prevented a sense of alienation or abandonment. Patients were kept at home within their comfort zone, unless hospitalisation was necessary, and this maintained the traditional family order. Thus, home may be the preferred place of care for Lebanese patients in need of palliation though this needs future exploration and research (Soueidan et al., 2018). During hospitalisations family members were always with the patient, engaged in coordinating medical consultations with the health care providers, dividing tasks among family members, securing essential medications, ensuring the patient received personal care and social support. This family involvement is comparable to the emotional, medical and financial support family caregivers provide to cancer patients in Nigeria, Zimbabwe and Uganda (Adejoh et al., 2020). Though patients' character and behavioural patterns were altered due to the serious illness, the essence of the relationship between patient and the primary caregiver was preserved with kindness and respect. This nurturing relationship made the social interaction meaningful to both sides as patients found comfort and took pride in their children or partners, whereas family caregivers found spiritual harmony and purpose through fulfilling filial duties. Similar to other Middle Eastern communities, the dignity of the patient was somewhat intertwined, reciprocal and interdependent with that of the family caregiver, where the wellness of one positively reinforced that of the other (de Graaff et al., 2010; de Voogd et al., 2021).

8.3.1.4 Compassionate and health care equity

With the dominance of the private sector and absence of universal health coverage in Lebanon (see Chapter 2), access to good health care is a privilege incurring a huge financial burden on the impoverished subgroups (Ammar, 2014). Accessibility to health services is not only affected by socioeconomic class but also by geographical area, politics, sectarianism, and religious party

affiliations that marginalize those who do not claim to be active members of a political or religious groups (Isma'eel et al., 2020). Lebanon's health care system has been further stretched with the influx of Syrian refugees that increased the demand of health services, depleting resources and destabilizing the infrastructure (Dumit & Honein-AbouHaidar, 2019). Similar to a health care systems such as the U.S., socioeconomic wellbeing is regarded a crucial feature to access a dignified health care experience in Lebanon (Ohlson, 2020).

Both patients and families trusted mainstream Western medicine that uses technological interventions to restore health and wellbeing. They were keen on seeking symptom relief even if that entailed visiting many clinicians with expensive fees. Patients and family caregivers wanted to be taken care of by physicians and nurses who are attentive, empathetic, kind, ready to dedicate enough time to listen, establish rapport and respond to patient needs (Johnston & Smith, 2006). Health care providers' caring presence and supportive input, which is mindful and empathetic to the physical and psychosocial needs of the patient, improved patient experiences of dignity. In contrast, there was a lack of dignity for patients receiving care from health providers in a rush (Bagherian et al., 2019; Dakessian SAILIAN et al., 2021; Greer & Joseph, 2015; Hackett, 2017; Östlund et al., 2019).

Both patients and families wished to receive information. They anticipated clear and timely responses from health providers explaining the details of the plan of care. Family caregivers required a friendly approach, gentle communication with some kindly humour to uplift patient morale and dignity (Dean & Gregory, 2004). Similar to Western societies, incomplete disclosure of information, or healthcare providers not committing sufficient time or curiosity to listen to a patient's story, or rushing to finish the clinical visit claiming that other patients are waiting, or

an absence of the physician in times of hospitalisation, were regarded to be disrespectful, unethical and compromising of patient dignity (Harst de et al., 2018). A compassionate presence of health providers that employ effective communication with simple language seems to be a universal patient need in different parts of the world (Fern ndez-Sola et al., 2012; Palfrey et al., 2016).

Though most patients and family caregivers reported positive experiences of dignity while receiving care in health institutions, many had negative observations towards physicians or nurses due to incidences of mistrust, non-transparency, or miscommunication between the parties. For instance, a family caregiver expressed how distressed she was when nurses applied physical restraints on her mother, who was agitated, without informing her or obtaining her consent. Others were concerned that physicians often share incomplete information with the patient about medical care or the plan of management leaving them in a helpless or undermined position. Some were unhappy with the delayed nursing services on the wards that kept patients waiting for care, or when nurses depended on family members to deliver patient personal care.

Having access to health services or medications was regarded as a privilege, and a challenge for patients who were experiencing financial worries and personal hardships to access care. For instance, patients felt humiliated with the long waiting hours at the Lebanese ministry of public health to receive medications and often the unavailability of the medicines. Some patients and family caregivers who did not have personal medical insurance reported that the quality-of-care provided by nurses and physicians was not universal and differed depending on the socioeconomic rank of the patient. Longer visits and better attention were provided for

wealthier patients while the impoverished were marginalised. Favouring patients of high social or economic status raises ethical concerns about equity in medical care, especially in times of crisis, when there is an even greater need to protect patient dignity (Cheung & Parent, 2021; Choo, 2019).

8.3.2 Themes that diverged in patients and family caregivers' perceptions

8.3.2.1- Disclosure and its relationship to personal autonomy

A point of difference between family caregivers and patients' accounts was where families withheld the diagnosis from patients as opposed to the patient's wish to know their diagnosis and prognosis. All the younger patients with a cancer diagnosis that were interviewed were informed about their condition, treatment plan, and prognosis. One family caregiver described their intent to conceal the bad news from his mother on the assumption that the knowledge of being diagnosed with cancer would demoralize her and compromise her dignity. Like other patients with cancer, Lebanese patients often wish to be informed of the truth of their diagnosis, especially when the disease was at an advanced stage (Doumit & Abu-Saad, 2008; Temraz et al., 2019). However, Lebanese family caregivers intended to avoid telling their relative, in order to protect them from the harsh psychological pain of knowing about their expected death. Non-disclosure of diagnosis is a common practice in Eastern, Asian, and south American cultures (Bou Khalil, 2013; Arunangshu Ghoshal et al., 2019; Torres & Rao, 2007; Wang et al., 2018; Yoshida et al., 2012). Such a desire to keep the diagnosis or prognosis a secret, may be the result of the stigma associated with cancer and the family caregivers' unpreparedness to accept the grave condition (Lewis et al., 2020). This also indicates death anxiety in family caregivers when faced with dying member (Lau et al., 2018).

The high degree of family involvement and control over prognostic disclosure complicates the general communication and disclosure practices around patients. This places family members and physicians in the position of, at times, undermining the patient's rights and preferences (Chaturvedi et al., 2014). Since illness and death are a collective experience, acknowledging the patient's autonomy as well as considering the opinions of family and wider network, may be more suitable in the Lebanese context. Respect for individual autonomy and self-determination at the end of life may not be the core focus of upholding dignity in Lebanese culture, as it is in North American and North European countries (Andrea Rodríguez-Prat et al., 2016). But it can still be part of the collective interdependence and interrelatedness of family members and sociocultural norms that shape clinical interactions and dynamics of the communication (Lewis et al., 2020). The close connectedness of the patient amid the family unit shifts the delivery of care from patient-centeredness to that of addressing the needs of the immediate family (Gómez-Vírseda et al., 2019).

8.4 Evaluating the findings against the Chochinov Model

In this section the findings are compared with the empirical Model of Dignity (Chochinov, 2002). The Chochinov Model is selected for assessment because a) the model revolves around patient dignity in palliative care and b) it is an established, evidence-based conceptual framework dominant in the literature of palliative care and often employed to guide dignity research, design measurement tools, strategies or interventions in promoting patient dignity at end of life (Chochinov et al., 2005).

As discussed in Chapter 2, Chochinov’s Model (figure 2.1) comprises three main categories, nine themes and 15 sub-themes of the perception of dignity in patients with terminal cancer. Each category of the Dignity model is elaborated and compared with the study findings.

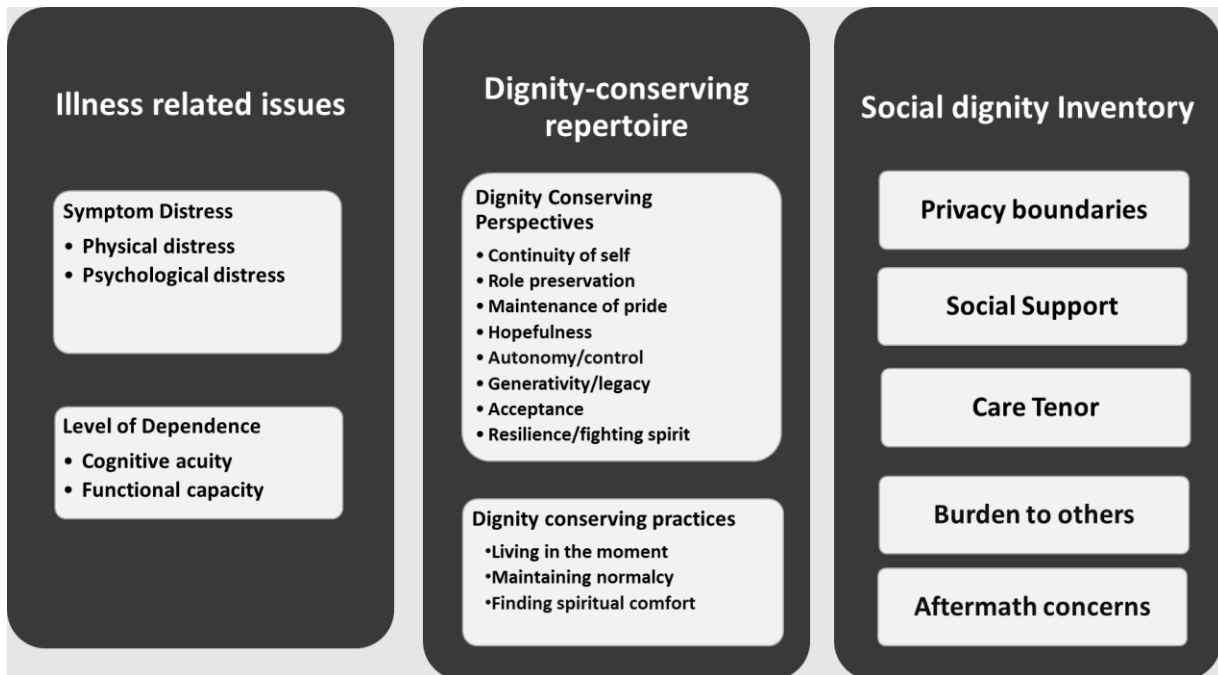


Figure 8. 2 Chochinov’s Model of Dignity (2002)

Though the model is created in a different geographical, economic, and cultural context, it shows overall coherence to the findings from a Lebanese setting. Most of the themes of the Chochinov Model were apparent in the findings with variations in emphasis or interpretation. The Dignity model was constructed from a Western viewpoint after interviewing hospitalised patients with terminal cancer who were receiving palliative care services in Canada. The ethnic affiliations of the participants were not mentioned in the study.

In this section, the findings are discussed against each category and theme of the Chochinov model. In the current study, two new sub-themes of dignity were identified: a) outer

appearance, b) equitable and affordable care. Faith and family support were the predominant overarching themes that were central to protecting and supporting dignity for patients with palliative needs. Some of the sub-themes identified in the Chochinov model appeared with less emphasis or had a different interpretation such as physical distress, social support, autonomy, role preservation, generalisability / longevity, and privacy boundaries. On the other hand, two of the sub-themes, burden to others and aftermath concerns, were of lesser importance in the patients' findings.

8.4.1 Categories of the Dignity Model

A) Illness related concerns: The analysis identified that maintaining physical independence, functionality and cognitive wellbeing and good memory are important elements in maintaining dignity. Patients who felt debilitated, needed help from others to perform daily tasks or routines, or experienced decreased mental capacity such as loss of memory experienced diminished dignity (Choo, 2019; A. Rodríguez-Prat et al., 2016). Symptom burdens such as pain or muscle weakness deprives patients of physical ability to continue the routines of their daily lives, diminishing their dignity (Franco et al., 2019 ; Guo & Jacelon, 2014). However, physical symptoms such as pain and breathlessness did not appear as a strong theme when patients were asked about their dignity. This might be due to conducting interviews with patients residing in the community instead of hospital setting, where their illness may be at a more acute or severe stage. However, prompt attention to symptoms was regarded to be crucial to maintaining patient dignity during hospitalisations, or in the home setting. The vagueness or uncertainty of the illness and loss of control evoked anxiety in all the interviewed patients.

Preserving the outer physical appearance was crucial for preserving self-image and dignity escaping stigma and open discussion about the illness. Physical appearance and maintaining the form of the previous body, particularly to women, is a new theme that is not mentioned in the model. The fundamental need to appear well, to maintain self-identity and peer relationships was important to European, Asian as well as Eastern Mediterranean patients, in refocusing attention from their illness to that of self (Cheng & Chen, 2021; Dakessian Sailian et al., 2021; Tollow et al., 2020).

B) Dignity Conserving Repertoire: Family caregivers and patients with palliative needs heavily emphasised faith within an organised religion as a significant coping practice that invoked inner strength and *resilience* during the illness. As patients accepted the illness to be delivered 'from God' their *continuity of self* and worth was preserved because personhood and dignity transcended the ill health status. Dignity was protected through a devoted relationship and belief in the omnipresent Creator that was a dominant theme across the data. Faith was not only a practiced ritual but also assisted patients in *accepting the illness, staying resilient*, continuing and holding on to a glimpse of *hope* for cure or enhancement of health. Faith and religiousness have been associated with *resilience* underpinned with finding meaning in life in palliative care patients from multiple cultures (Fombuena et al., 2015). It is worth mentioning that the fighting spirit was not prominent, particularly in older patients who seemed to accept their condition. Relying on religious beliefs is a common practice different countries where the importance of knowing God's might, accepting His authority, and respect to family values supersede values of individualised choice or self-expression (*The Inglehart-Welzel World Cultural Map - World Values Survey Source 2020*).

Role preservation in the family hierarchy secured a sense of normality for patients. Envisioning the father as the breadwinner and the mother as the source of caring of the children affirmed the impact of traditional family roles in the experiences of dignity at end of life. Traditional gender roles and family structure are prevalent in low-income and highly religious countries (Archer, 2014; Inglehart, 2020). Participants navigated their agency through the social order and cultural norms that shaped behaviours and expectations (Gott et al., 2020).

Married patients relied on their children and spouses to uphold their dignity as they were regarded to be their source of *pride and legacy* for life. All married interviewed patients had children, and fertility was regarded the way for continuity of the self and their legacy after death. On the other hand, single patients found legacy and pride in their personal achievement such as career or community involvement. Younger patients were eager to maintain self-respect within their career successes and business opportunities, while older patients were more accepting and resigned to the illness. To maintain normality patients longed for social outings that involved friendly gatherings, and entertainment to reinforce identity and dignity (Franco et al., 2019). The sub-theme of Individualistic autonomy or choices in medical decision making or a plan of care was not evident to be a fundamental element of patient dignity. Due to the intense interdependence of patient within the family fabric, decision making did not emerge as a solo practice but a relational and contextual process, involving collective sharing and decision making amongst the family members (Gómez-Vírseda et al., 2020).

C) Social Dignity Inventory: For Lebanese patients, dignity was generated through social interactions and connectedness that happened through visits from friends and family, living in the family circle, receiving support, with only a limited use of nursing homes. In the hospital

setting, the family presence was crucial to the patient to maintain worth, respect, identity, and dignity. Maintaining good health and dignity was felt to be preserved by keeping the diagnosis of terminal or advanced illness among the immediate family members. Thus, *privacy* was interpreted not only as privacy of the body while receiving health services as illustrated in the dignity model, but also in the community setting where patients and family caregivers kept the illness to themselves. Another nuance that explains the desire to maintain secrecy of the diagnosis is the concept of '*gossip*', that could violate patients' and family caregivers' privacy and dignity (de Graff et al., 2010). *Social Support* received by the family members and children preserved the worth of the patient in the family hierarchy as a parent or a spouse, nurturing the interpersonal relationships, fostering agency and dignity. Patients focused and relied on the tight relationships they had with their children, spouses, and close friends as a source of support during illness, that was rarely substituted with other means of support.

The tenor of care from formal caregivers, such as physicians and nurses was regarded as an important element to safeguard or threaten patient dignity while receiving health services. Dignity was enhanced by healthcare providers taking an attentive approach, providing quality time and timely response that was dependable and warm. (Johnston & Smith, 2006).

Compassionate care with healthcare providers giving clear explanations and information about the patient's illness was congruent to patient preferences supported patient dignity in health care settings (Guo & Jacelon, 2014). Patients needed accessible services that are offered equitably to all citizens regardless of rank, age, gender, or political affiliations. Lack of coordination among health professionals that resulted in delays or ineffective care, hasty clinical encounters, or missing information reduced experiences of patient dignity. On the

other hand, being a *burden to others* was not prominent in the findings. This could be due to the prevalent norm of caregiving being the default responsibility of close family members.

Aftermath concerns appeared in a few of the patients but was not identified across the data.

The majority of the family members were concerned about securing a good quality life for the patient by ensuring daily personal and medicinal needs were met. They associated economic wellbeing as a precondition to maintaining patient dignity, as financial hardships, and poverty limited access to needed resources. Economic welfare is an underpinning necessity that is absent from the Model. The sub-theme of *equitable and affordable care* emerged as crucial to preserve patient dignity while receiving health services. Inequalities and health disparities among citizens based on social class damaged patient dignity as it restricted access to essential health services (Chen & Cammett, 2012). Due to the political instability and the dysfunctional public health care system in Lebanon during the past year, essential drugs and tools were hard to get and often had to be smuggled to the affluent families (MSF, 2021). Jacobson (2009b) mentions that patient dignity is violated in any social order of inequality such as in the health care system. Inequalities in resources or material supplies creates huge disparities, deprivation and an asymmetrical environment, denying the poor adequate health care access that is needed.

The Chochinov model of Dignity was developed in Canada (Chochinov, 2002) within an integrated national health insurance plan where the government pays for almost all health services with negligible co-payments from consumers (Ridic et al., 2012). The Chochinov model assumes the presence of a robust health care infrastructure, within a politically stable macro environment, and with accessible medical services that provide equal care to its citizens. It does

not consider political and economic instability, influx of refugees, high poverty levels and a dismantled government that can be detrimental to health outcomes and experiences of dignity (ESCWA, 2021b; Landry et al., 2020). The fragile socio-political situation in Lebanon, compounded with geopolitical turmoil, corruption, unparalleled economic crash, limited medical supplies, and uncontrollable events such as the devastating port blast, inevitably compromises patient experiences of health care, safety, and dignity (Landry et al., 2020). Economic and political forces are key players in shaping patient experiences of dignity in the health care sector in various Middle Eastern countries in conflict (Al-Saiedi, 2021; Dakessian Sillian et al., 2021; Tsurkov & Jukhadar, 2020).

The Covid-19 pandemic created an additional strain on the health care system where palliative care patients experienced shortage of staff, scarcity of essential medicines and medical supplies, together with a heightened stigma of a potentially deadly infection, and restrictions imposed on family visitations (Isma'eel et al., 2020). The right to receive health care remained at the mercy of environmental factors, governmental initiatives, and international policies. The arrays of these complex factors interfere with patient experiences and perceptions of dignity in a country such as Lebanon.

In Figure 7.3 the Chochinov model of dignity is presented with the variations that emerged from the study. In the first category of Illness related concern, a new theme of *outer appearance* is added with its sub-themes of *stigma and death anxiety*. A star is placed next to physical distress to denote that physical symptoms were not openly mentioned as an influencer of dignity in the findings. In the second category of dignity conserving repertoire, *role preservation* and *generalisability / legacy* were related with the role of the patient in the family hierarchy who

found pride and comfort in their siblings and their achievements. *Autonomy* was interpreted as relational not purely individual and connected to the patient’s immediate family members. Faith emerged as a central theme in protecting dignity and not an optional coping measure. Finally, in the Social Dignity Inventory as mentioned previously, *privacy boundaries* extended from personal bodily privacy to the social and collective dimension leading some to hide their diagnosis. *Social support* mainly constituted family closeness to the sick and the last two themes of *burden to others* and *aftermath concerns* were less obvious in the findings. A new theme of *equitable and affordable care* underpinned by economic sustainability was added.

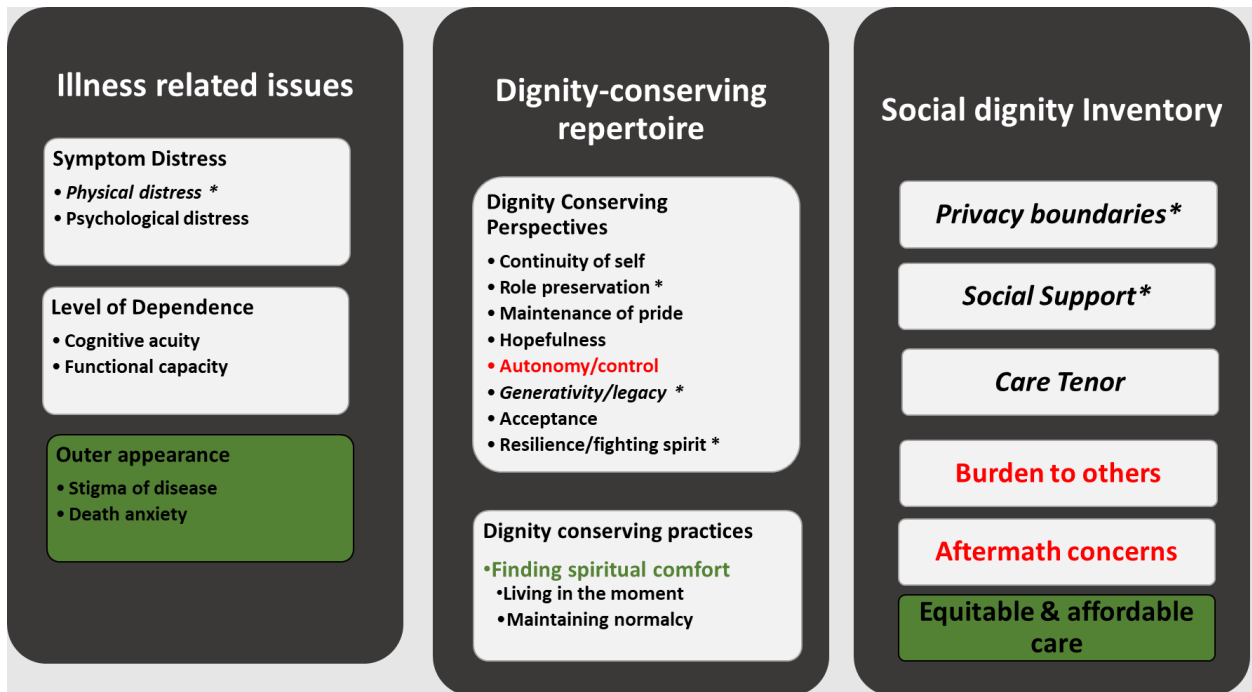


Figure 8. 3 Chochinov’s Dignity Model adjusted in light of the new findings.

* Sign refers to a modified interpretation or emphasis. Green shaded boxes refer to a new sub-theme added to the model. Red letters refer to the non-dominance of the sub-theme in the new findings.

8.5 Synthesis of the Findings

According to the findings, a sense of dignity in patients from the Lebanon with palliative needs has multiple layers that stem from the individual, extends to the inter-relational, to the community and to the broader societal arena. The core of the dignity experience is a spiritual foundation, reinforced through religious practices, that nurtures an absolute sense of dignity during illness. Patient dignity is violated when the individual is vulnerable, weak, and has lost cognitive, physical, or social integrity becoming dependent on others (Jacobson, 2009 a, b). Dignity is at a dynamic interplay, often reciprocal, with close social relationships and connectedness (Choo, 2019) within the patient's immediate family as well as encounters in the health care environment. Dignity is inter-relationally dependent on the social position of the individual in the family, the health care setting, and the overall societal and economic climate that promotes or diminishes patient dignity (Enes, 2003, Jacobson, 2009; Periyakoil et al., 2010; van Gennip et al., 2013). Relationships in which one of the parties is undervalued or has insufficient information, and having less power may generate the experience of losing dignity (Jacobson 2009). Unequal access to health care services, insufficient resources, poor-quality or discriminating health care and overall impoverishment of living standards violate patient's dignity. In this regard, political forces may pull down the dignity of individuals through tensions, instabilities and policies reinforcing division and unequal care.

The lotus flower with its petals articulates the components of patient dignity with palliative needs (see Figure 7.4). This lotus flower was created because it symbolises spirituality, the cycle of life and harmony amidst conflicting emotions that has a close resemblance to palliative care patients (Stanton, 2021). The petals of the lotus flower represent the themes of the study.

Patient dignity is rooted in individual spirituality and connectedness to the Creator making it the essence of the flower. Ethical values and the inherent relationship and longing for the Creator anchor a sense of dignity. Immediate social and family support, cultural norms that seem to have a spiritual value, generate experiences of self-worth and legacy. This relationship is strengthened by physical fitness and mental wellbeing. Beyond the family, dignity is supported through an accessible health care system that is compassionate and attentive to patient needs. Health services that are timely, effective, efficient and equitable promote dignity (World Health Organization, 2021). Nevertheless, as depicted in the figure 7.4, the lotus flower is stabilised and rests on a safe geopolitical and economic order representing a macro environment that promotes a citizen’s dignity. It is important that the overall climate promotes the safe acquisition of resources crucial to sustain this flower of dignity.

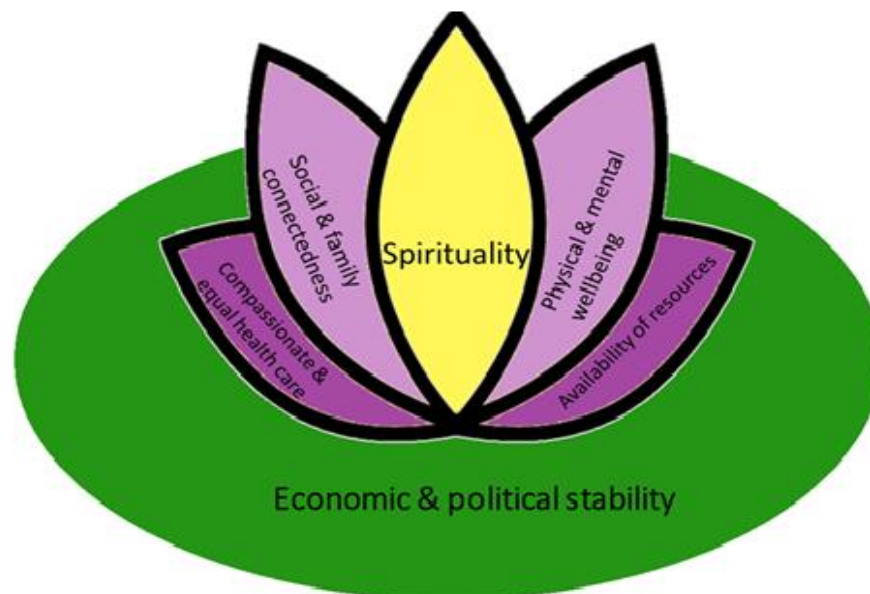


Figure8. 4 The Dignity Flower / Lotus

The flower depicts the dignity of patients with palliative care needs as multi-layered, multi-dimensional and a 'sum of distinct parts' playing unique, yet complementary, roles. The dignity flower has in its centre the spiritual dimension (faith) as the core (like the pistil of a flower) expanding immediately linked to the two 'petals' that of the physical and mental wellbeing, and social and family connectedness. Enveloping the 'petal' of the dignity flower are the two layers of the compassionate equitable health system, and availability of health resources in the health care system. Finally, the flower is established on a safe and sustainable platform underpinned by a stable socio-political and economic base (receptacle).

8.6 Personal Reflection

I started this PhD journey at a time when Lebanon was in a relatively stable state. I did not worry about the economic welfare or the future of my family. Now that my research is approaching its end, the overall political and economic condition has evolved dramatically, creating huge social and economic devastation on all its citizens and a decay of essential infrastructure. Given the overall chaotic situation of the state and scarcity of basic needs such as electricity and fuel, I am grateful to have been able to achieve my PhD research this far. I want to reflect on some of the challenges and memorable moments I experienced during my endeavour.

The pace of the research slowed down due to the Covid-19 pandemic. The intensifying political uproar and daily strikes run by regular people and organisations also led to the slow processing of the ethics committee at the American University of Beirut's (AUB) leading to the delay of the approval for a couple of months. It is worthwhile to mention that I had to change the data collection method in the proposal from in-person interviews, to online or telephone. Securing

the final ethical approval took around six months. That summer, I spent most of the days coding and analysing my systematic literature review in my in-law's country house in Anjar where the electricity power cuts were less, and relatively far from political repercussions such as road closures. Once the results of the systematic review came out, which mostly reflected the Iranian condition of patient dignity, I was resistant to see the similarity of the results to Lebanon. I perceived Lebanon as a modern and an economically rich country that has a strong health system equipped with the European and American medical supplies. Now looking back to the results, I sadly see a huge similarity in the condition and experiences of patients in the two countries.

In September 2020, I interviewed my first patient who received home-based palliative care. This was one of the rare interviews I conducted in a participant's house. I still remember how the participant, a married man suffering from rectal cancer, with a large family, welcomed me warmly into his house. Though I belonged to a different sect and ethnic group he was very respectful. Halfway into the interview, he was filled with emotions and lit a cigarette urging me to smoke with him. After resisting the cigarette his eldest daughter offered Lebanese coffee and apples. His grandchildren were in the same room, some playing on the floor, some taking a nap. He was generous and did not ask for privacy for the interview. He wanted to help hoping he could receive a cure of his condition through the research. I realised how the patient, as a father, perceived himself as the anchor of the family and the family unit, which embraced all the members with all their needs as if 'all is one and one for all' motto was a reality. He did not ask for privacy, although he was suffering from rectal cancer, an intimate area with sensitive implications. I explained that the research was about understanding how the dignity of patients

is understood and how it can be protected during advanced illness, and it did not mean to offer any cure.

It took more time than estimated, nine months, to recruit participants and complete the interviews. With the Covid-19 lockdowns and waves of high infection it was very challenging to recruit. I was happy to have opted for telephone calls for data collection since at that point I realised the pandemic was not going to be over quickly. The data analysis process was very intriguing. The NVivo qualitative analysis software was very useful in organising my codes. The analysis was an iterative process that allowed me to unpick salient and latent themes as the interviews settled in my mind and allowed me to rethink and have further reflections. The write up of the findings evolved with time as there was always the chance to improve the structure and transcend mere description. Because English is my second language, it has always been a pursuit to ensure my English writing and speaking are at the expected level. I was lucky to have the opportunity to present the findings to a friend based in Denmark, to assess if she, a relatively outsider from the context, could comprehend and make sense of my findings, and inform aspects of the data I had missed.

Looking back at the time and efforts spent in this work, I realise that this journey, though challenging with uncontrollable events, has changed me to a humbler and wiser human being, capable to comprehend multiple cultural systems and perspectives. Encounters with patients and family members during data collection as a researcher, allowed me to broaden my point of view learning more about dignity and how overlooked details, like personal outlooks, social encounters, relationships, embedded hierarchies and power systems, and language may shape dignity and satisfaction with care. This endeavour was an overall long training session that

taught me to rely on myself and realise that the field of palliative care offers a vast landscape to experiment.

8.7 Implications to practice, policy, and research

The study provides insight into improving patient experiences of dignity in palliative care, by identifying conditions that patients and family caregivers saw as necessities to uphold or diminish dignity and worth. Thus, the findings may potentially pave the way to practical implications, initiatives, changes or suggestions to ordinary individuals, families, communities as well as professionals in the field of medicine, nursing, allied health care, educators, and policymakers. The findings also have relevance to neighbouring countries with similar geopolitical, socioeconomic, and cultural constructs, which could guide stakeholders into ways of maintaining dignified experiences for patients with palliative care needs.

8.7.1 Implications for practice: Since being surrounded by family is a crucial element for a patient's perception of dignity, clinicians and health administrators need to be sensitive to the patient's need to have family present at the point of care allowing family visits. Visiting hospitalised patients was prohibited or limited during the pandemic, which has the potential to influence dignity negatively. Health providers need to dedicate ample time listening to patients' and family's needs, values, and preferences. For instance, family caregivers were upset when invasive interventions, such as inserting a nasogastric tube, was started by health providers without first attempting non-invasive ways of feeding. Throughout the findings, involvement of the family in providing patient care is highly desirable for patients and family caregivers as they constituted a central source of social, health, and financial support .

Since family presence is vital, providing palliative care services at home would be of invaluable mode to promote dignity of the patient. , Home based services are currently only offered as isolated services in the country. With the absence of governmental support, home-based affordable palliative care could be accomplished in partnership with health professionals, civic societies, community initiatives and families (Kellehear, 2013; Reid et al., 2017).

Since faith and the centrality of God is dominant in the lives of the patients, providing spiritual support and facilitating for spiritual/ religious practices in the hospital setting is also recommended as faith is an important coping mechanism for patients and family caregivers during illness, contributing to positive sense of security and hope that preserves dignity.

The patients wanted to stay socially connected. Thus, the initiation of virtual support communities through digital applications where patients and families can exchange and receive emotional, social, medical, and spiritual support could be planned, for instance via social media like WhatsApp, which is commonly used by the patients as a means of communication (Dhiliwal & Salins, 2015). The psychosocial support experienced from such virtual communities can enhance a sense of connectedness, safety, and dignity in patients with advanced conditions. This can reduce social isolation, as is evident in the findings as well as the systematic review (Dakessian Sailian et al., 2021). These applications have proved particularly useful during the Covid-19 pandemic with telemedicine and remote consultations shown to be a supportive tool to patients unable to travel to the health care institution (Worster & Swartz, 2017).

Educating all health care team members, clinicians, students and faculty in the health and allied health domains about key elements and values of dignity for Lebanese patients and their

families and how to preserve it, would be useful in tailoring the clinical approach and dignity interventions accordingly. It is vital to incorporate quality indicators in planning and implementing health services by setting guidelines and actions that safeguard patient dignity (World Health Organization, 2021).

It is worth noting that alongside health care institutions, a public health approach would offer a holistic method to integrate palliative care services and awareness to assist patients and families in maintaining and preserving their dignity in their homes, neighbourhoods, and communities. Community development through the mobilisation of churches, mosques, schools, businesses, social clubs would assist in addressing the challenges and needs of maintaining dignity and integrity of patients with palliative care needs (Sallnow et al., 2012).

Compassionate communities built through community engagement and supportive networks would potentially address the gaps in access to palliative care and tap into the untouched resources of social and spiritual care, providing for the day to day needs of the patients helping to build resilience (Abel, 2018; Kellehear, 2013).

8.72 Implications for Policy: Since not all have access to quality palliative care resources, it is crucial that a national strategic plan for universal health care coverage is planned carefully and implemented based on the principles of equity and social justice that funds health care. This would aim at reducing the gap in accessing health services, providing affordable quality services to all citizens and promoting patient/ family dignity. Equal access to quality health services is an imperative to preserve citizen's rights and dignity (The United Nations General Assembly, 2019). This progress is not anticipated to happen soon in Lebanon due to the pandemic and the immensely disrupted socio-political condition in the country. New policies

may also be devised to financially support the individual with serious illness and the immediate family caregiver, as patients rely mostly on their families and adult children for sustaining quality of life and financial support.

Palliative care policies should be clearer about the responsibilities and duty of physicians in discussing diagnosis and initiating end-of-life discussions with patients early in the course of incurable illnesses, as patients are keen on having information about their condition to maintain dignity. The clinician needs to explore the extent of information the patient wishes to know and gauge the discussion accordingly. It is expected that the clinician is capable of addressing patient and family needs, resolving any conflict that may arise, with regards to disclosure of diagnosis or plan of care. Legalising the requirement for healthcare providers to approach these serious yet delicate conversations would pave the way to the process of advance care planning. This could potentially empower patients and families to plan for the patient's end of life in relation to their understanding of dignity and acknowledging that death is inevitable (Balaban, 2000).

8.7.3 Implications for research: having explored patient and family interpretations of dignity, it is important to understand the perception of dignity from the health care professional's perspective and assess whether there is coherence to the findings of this study. It would be interesting to pilot the patient dignity inventory-assessment tool by Chochinov et al. (2008) and examine its applicability with the addition of new domains of faith, family presence, and accessibility of compassionate health services, with variations in emphasis amended for the Lebanese context. Within the clinical setting, it would be interesting to explore how the dignity therapy (Chochinov et al., 2005), or dignity care interventions (S. McIlfratrick et al., 2017)

implemented by nurses would fit in the Lebanese setting to alleviate psychosocial distress at the end of life.

The analysis of this study instigates the exploration of other questions, such as the role of gender in the perception of dignity, and the experiences or situations that hamper dignified experiences in palliative care. It is pertinent to also explore how death and dying is perceived by patients, health workers and families in the Middle Eastern setting and how this understanding may impact the delivery of quality palliative care services. Disclosing diagnosis and prognosis to patients and family caregivers, and the readiness of stakeholders in sharing information and knowledge through sensitive but honest conversations is another area that needs to be explored to have a deeper understanding of the dynamics of all stakeholders.

Most of the participants in the study knew about their condition, this may indicate that practices may be changing in the Lebanese culture towards more respect to patient preferences around disclosure. It would be important to explore how end of life communications are shaped with sociodemographic factors such as age, gender, education level, cultural norms, or ethnic, geographical groups as Lebanon has a heterogenous population. See Table 7.1 summarising recommendations by stakeholder.

Table 8. 1 Recommendations to preserve patient dignity in palliative care

Health Providers	Health Administrators	Educators	Policy Makers
<p>Enhance effective communication skills:</p> <ul style="list-style-type: none"> a) Dedicate ample time to listening and attending to patients' needs b) Active and timely attention of physicians and nurses on the medical wards c) Explore how the communication is preferred from the patient perspective: with the patient and family, only patient or only family d) Provide clear and honest information to the patient regarding diagnosis, the plan of care, treatment and prognosis, unless the patient chooses not to know. d) Provide family support 	<p>Incorporate quality considerations in planning and delivering care to individuals that are patient-centred and safeguard dignity:</p> <ul style="list-style-type: none"> a) Ensure the presence of a multidisciplinary palliative care team b) Ensure the availability of spiritual support in the health care/ palliative care team c) Explore the possibility of providing palliative care at home 	<p>Train health providers about the importance of maintaining patient dignity whilst delivering care to patients with palliative needs:</p> <ul style="list-style-type: none"> a) Teach about patient and family understanding of dignity and means of preserving it in the clinical or community setting b) Train healthcare workers to deliver compassionate and equitable care that is inclusive of all patients to ensure dignity. c) Train about culturally sensitive communication skills regarding end-of-life care that does not violate dignity. 	<p>Incorporate national policies that addresses needs of palliative care patients:</p> <ul style="list-style-type: none"> a) Plan for universal health care coverage that funds palliative care services and allows equal access to all b) Devise policy that holds health providers accountable for sharing clear information with the patient about management and plan of care aligned with patient wishes c) Plan and implement community-based initiatives to increase awareness about dignity of patients with pall d) Provide adequate support to family caregivers of patients with palliative care needs.

<p>Integrate spiritual care in health care settings: Facilitate space for patient's spiritual time (prayer, reading.)</p>	<p>Family visits: a) Allow the presence or visits of at least one family member in the hospital with the patient</p>		<p>Support (practically, economically) family caregivers in providing care</p>
<p>Provide equal and quality health services to all patients without discrimination regardless of social or economic class or political affiliation</p>	<p>Make palliative services affordable to all patients</p>		<p>Increase affordable home-based palliative services and support those organizations (NGOs) that provide palliative care</p>
			<p>Start community initiatives that have a public health care approach</p>

8.8 Strengths and Limitations

This research provides an initial understanding of the concept of dignity within palliative care in a country where research in palliative care is scant. The strength of this project is that it unveils a topic unresearched from an Arab – Lebanese perspective where the sample studied was diverse in terms of age, gender, medical condition, and ethnicity. The findings show overall consistency with the global literature and the Model of Dignity by Chochinov (2002). Also, the use of snowball sampling was a successful strategy in recruiting vulnerable participants (Sadler et al., 2010), where research participants were asked to refer to potential patients or caregivers of their acquaintance for enrolment.

Due to the covid-19 pandemic much of the data was collected through telephone calls where the participants' actual home or real environment and context was sometimes missed.

However, using telephone calls has provided more access to participants and allowed participants to discuss sensitive issues maintaining confidentiality and privacy (Block & Erskine, 2012; Mealer & Jones, 2014).

The findings are affected by the socio-political and economic state of the country as well as the Covid-19 pandemic. The harsh conditions in Lebanon affected by local protests, devaluation of the Lebanese currency, unemployment, and interrupted governmental services, the massive port blast, brought forward the need for equitable care that makes no social, ethnic, or political discriminations among patients. It highlighted the need for the availability and accessibility of essential medicine and health resources for maintaining health, wellness, and dignity. Thus, it is possible should there have been economic and political stability the findings may have had a different emphasis.

Finally, not exploring the perspective of health care providers might be considered a limitation hindering the holistic understanding of the topic of dignity within palliative care. The perspective from health care providers needs to be studied in later research to complement the findings.

8.9 Conclusion

Patient dignity in palliative care is a multifaceted, contextual phenomenon determined through the intersection of the complex social, economic, political, health, religious, and individual factors that may support or damage dignity. This study adds to the body of knowledge on dignity in palliative care, unveiling a nuanced understanding of dignity from non-Western patients and families and highlighting that context is key to its understanding.

Dignity is a dynamic concept and the recent dire conditions in Lebanon, as well as the Covid-19 pandemic, have significantly shaped its experience and interpretation. The study reveals how patient dignity is delicate, volatile, easily affected by public policies, governments, sturdiness of health services, accessibility and equity of care, and the proximity of social family ties. Unlike the Western literature, the study also uncovers the immense impact of religion and faith and the effect of traditional norms and culture on improving the experiences of dignity.

This is the first study in Lebanon to document what palliative care patients need to maintain their dignity. Patient dignity is fostered through living a good quality of life that is enacted through general wellbeing, preserving family traditions, faith, economic abundance, and inclusiveness. Patients and family caregivers strive to receive equal care that does justice to all socioeconomic layers of the population. The three categories of the Chochinov Dignity model are supported in the findings with variations in emphasis and interpretations. The new themes

developed in this study extend the Chochinov model by revealing that political turmoil, poverty, shortages and limited accessibility of medical resources, act as an overpowering threat jeopardising patient dignity and increasing gaps of inequality in receiving quality services.

References

- Abdel-Malek, R., Farag, D., Shohdy, K., & Cox, S. (2019). Availability of Informal Caregivers for Palliative Care Patients with Cancer: Is there a Difference between Higher- and Lower-Income Settings. *Indian Journal of Palliative Care*, 25, 379-382. https://doi.org/10.4103/IJPC.IJPC_199_18
- Abdulrahim, S., Ajrouch, K. J., & Antonucci, T. C. (2015). Aging in Lebanon: Challenges and Opportunities. *The Gerontologist*, 55(4), 511-518. <https://doi.org/10.1093/geront/gnu095>
- Abel, J. (2018). Compassionate communities and end-of-life care. *Clinical medicine (London, England)*, 18(1), 6-8. <https://doi.org/10.7861/clinmedicine.18-1-6>
- ACLED, A. C. L. E. D. P. (2021). *A new season of unrest in Lebanon*. Retrieved December, 29 from <https://reliefweb.int/report/lebanon/new-season-unrest-lebanon>
- Adejoh, S. O., Boele, F., Akeju, D., Dandadzi, A., Nabirye, E., Namisango, E., Namukwaya, E., Ebenso, B., Nkhoma, K., & Allsop, M. J. (2020). The role, impact, and support of informal caregivers in the delivery of palliative care for patients with advanced cancer: A multi-country qualitative study. *Palliative Medicine*, 35(3), 552-562. <https://doi.org/10.1177/0269216320974925>
- Al-Saiedi, A. (2021). *Challenges Faced by the Iraqi Health Sector in Responding to COVID-19* (Iraq, Issue. https://reliefweb.int/sites/reliefweb.int/files/resources/PHR_COVID-19-and-Health-in-Iraq_April-2021.pdf
- Al-Sudaid, F. (2021). *Lebanon is sick with a health system that is as costly as it is inefficient*. L'Orient-Le Jour Retrieved February, 27 from <https://today.lorientlejour.com/article/1259152/lebanon-is-sick-with-a-health-system-that-is-as-costly-as-it-is-inefficient.html>
- Aljawi, D., & Harford, J. (2012). Palliative Care in the Muslim-Majority Countries: The Need for More and Better Care. In. <https://doi.org/10.5772/32452>
- Almigbal, T. H., Almutairi, K. M., Fu, J. B., Vinluan, J. M., Alhelih, E., Alonazi, W. B., Batais, M. A., Alodhayani, A. A., & Mubarak, M. A. (2019). Assessment of psychological distress among cancer patients undergoing radiotherapy in Saudi Arabia. *Psychology research and behavior management*, 12, 691-700. <https://doi.org/10.2147/PRBM.S209896>
- Amininasab, S. S., Lolaty, H. A., Moosazadeh, M., & Shafipour, V. (2017). The relationship between human dignity and medication adherence in patients with heart failure. *Journal of Medical Ethics and History of Medicine*, 10(5).
- Ammar, W. (2009). *Health beyond politics*.
- Ammar, W. (2014). *Universal Health Coverage: Bridging the Gaps*. Ministry of Public Health Retrieved October, 3, 2021 from <https://www.moph.gov.lb/en/view/1287/universal-health-coverage-bridging-the-gaps>
- Ammar, W., & Hamra, R. (2013). Palliative care: Shifting medical models to restore cultural values. *Lebanese Medical Journal*, 61(4), 189-190
- Arawi, T. (2010). THE LEBANESE PHYSICIAN: A PUBLIC'S VIEWPOINT [<https://doi.org/10.1111/j.1471-8847.2009.00258.x>]. *Developing World Bioethics*, 10(1), 22-29. <https://doi.org/https://doi.org/10.1111/j.1471-8847.2009.00258.x>
- Archer, M. (2014, December 4). How Does Religion Influence Family Formation Decisions? <https://ifstudies.org/blog/how-does-religion-influence-family-formation-decisions>
- Avestan, Z., Rahmani, A., Heshmati-Nabavi, F., Mogadasian, S., Faghani, S., Azadi, A., & Esfahani, A. (2015). Perceptions of Iranian Cancer Patients Regarding Respecting their Dignity in Hospital Settings *Asian Pacific Journal of Cancer Prevention*, 16(13), 5453-5458. <https://doi.org/DOI:http://dx.doi.org/10.7314/APJCP.2015.16.13.5453>
- Avis, W. (2017). *Gender equality and women's empowerment in Lebanon*. K4D Helpdesk Report.

- Awad, M., & Andre, J. (2021). *Lebanon-Syria: Smuggling and sanctions, the new front line*. France24. Retrieved December, 29 from <https://www.france24.com/en/tv-shows/reporters/20210416-lebanon-syria-smuggling-and-sanctions-the-new-front-line>
- Ayoub, F., Fares, Y., & Fares, J. (2015). The Psychological Attitude of Patients toward Health Practitioners in Lebanon. *N Am J Med Sci*, 7(10), 452-458. <https://doi.org/10.4103/1947-2714.168663>
- Azad, A., Sernbo, E., Svärd, V., Holmlund, L., & Björk Brämberg, E. (2021). Conducting In-Depth Interviews via Mobile Phone with Persons with Common Mental Disorders and Multimorbidity: The Challenges and Advantages as Experienced by Participants and Researchers. *International Journal of Environmental Research and Public Health*, 18(22). <https://doi.org/10.3390/ijerph182211828>
- Bagheri, A. (2012). Elements of human dignity in healthcare settings: the importance of the patient's perspective. *Journal of Medical Ethics*, 38(12), 729. <https://doi.org/10.1136/medethics-2012-100743>
- Bagheri, H., Yaghmaei, F., Ashktorab, T., & Zayeri, F. (2012). Patient dignity and its related factors in heart failure patients. *Nursing Ethics*, 19(3), 316-327. <https://doi.org/10.1177/0969733011425970>
- Bagheri, H., Yaghmaei, F., Ashktorab, T., & Zayeri, F. (2012). Patient dignity and its related factors in heart failure patients. *Nurs Ethics*, 19(3), 316-327. <https://doi.org/10.1177/0969733011425970>
- Bagheri, H., Yaghmaei, F., Ashktorab, T., & Zayeri, F. (2016a). Relationship between illness-related worries and social dignity in patients with heart failure. *Nursing Ethics*, 25(5), 618-627. <https://doi.org/10.1177/0969733016664970>
- Bagheri, H., Yaghmaei, F., Ashktorab, T., & Zayeri, F. (2016b). Test of a Dignity Model in patients with heart failure. *Nursing Ethics*, 25(4), 532-546. <https://doi.org/10.1177/0969733016658793>
- Bagheri, H., Yaghmaei, F., Ashktorab, T., & Zayeri, F. (2018). Test of a Dignity Model in patients with heart failure. *Nurs Ethics*, 25(4), 532-546. <https://doi.org/10.1177/0969733016658793>
- Bagherian, S., Sharif, F., Zarshenas, L., Torabizadeh, C., Abbaszadeh, A., & Izadpanahi, P. (2019). Cancer patients' perspectives on dignity in care. *Nursing Ethics*, 0969733019845126. <https://doi.org/10.1177/0969733019845126>
- Baillie, L. (2009). Patient dignity in an acute hospital setting: a case study. *Int J Nurs Stud*, 46(1), 23-36. <https://doi.org/10.1016/j.ijnurstu.2008.08.003>
- Balaban, R. B. (2000). A physician's guide to talking about end-of-life care. *Journal of general internal medicine*, 15(3), 195-200. <https://doi.org/10.1046/j.1525-1497.2000.07228.x>
- Balabanov, T. (2019). *The idea of human dignity in western philosophy and culture*. Retrieved August 29, 2021 from https://www.shs-conferences.org/articles/shsconf/pdf/2019/13/shsconf_appsconf2019_01011.pdf
- Beck, A., Cottingham, A. H., Stutz, P. V., Gruber, R., Bernat, J. K., Helft, P. R., Wilhelm, L., Schmidt, K., Stout, M. E., Willard, C., & Johns, S. A. (2019). Abbreviated dignity therapy for adults with advanced-stage cancer and their family caregivers: Qualitative analysis of a pilot study. *Palliat Support Care*, 17(3), 262-268. <https://doi.org/10.1017/s1478951518000482>
- Beletsky, L., Ezer T, Overall J, Byrne I, & J, C. (2013). *Advancing human rights in patient care: the law in seven transitional countries*.
- Bentley, B., Aoun, S. M., O'Connor, M., Breen, L. J., & Chochinov, H. M. (2012). Is dignity therapy feasible to enhance the end of life experience for people with motor neurone disease and their family carers? *BMC Palliat Care*, 11, 18. <https://doi.org/10.1186/1472-684x-11-18>
- Bernat, J. K., Helft, P. R., Wilhelm, L. R., Hook, N. E., Brown, L. F., Althouse, S. K., & Johns, S. A. (2015). Piloting an abbreviated dignity therapy intervention using a legacy-building web portal for adults with terminal cancer: a feasibility and acceptability study. *Psychooncology*, 24(12), 1823-1825. <https://doi.org/10.1002/pon.3790>

- Bhattar, K. (2021). BLACK LIVES MATTER: The History of Policing in the US and Its Impact on Americans Today. *UAB Institute for Human Rights Blog*.
- Bidabadi, F. S., Yazdani, A., & Zargham-Boroujeni, A. (2019). Patient's dignity in intensive care unit: A critical ethnography. *Nursing Ethics, 26*(3), 738-752.
<https://doi.org/10.1177/0969733017720826>
- Bitar, N., Kattan, J., Kourie, H. R., Mukherji, D., & Saghir, N. E. (2020). The Lebanese Society of Medical Oncology (LSMO) statement on the care of patients with cancer during the COVID-19 pandemic. *Future Oncology, 16*(11), 615-617. <https://doi.org/10.2217/fon-2020-0252>
- Block, E. S., & Erskine, L. (2012). Interviewing by Telephone: Specific Considerations, Opportunities, and Challenges. *International Journal of Qualitative Methods, 11*(4), 428-445.
<https://doi.org/10.1177/160940691201100409>
- Booth, Sutton, A., & Papaianou, D. (2016). *Systematic approaches to a Successful Systematic Review* (2nd ed.). Sage Publishing.
- Borhani, Abbaszadeh, A., & Mehdipour Rabori, R. (2016). Facilitators and Threats to the Patient Dignity in Hospitalized Patients with Heart Diseases: A Qualitative Study. *International journal of community based nursing and midwifery, 4*(1), 36-46.
<https://www.ncbi.nlm.nih.gov/pubmed/26793729>
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4709810/>
- Borhani, Abbaszadeh, A., & Rabori, R. (2015). New Vision for the Dignity: Understanding the Meaning of Patient Dignity in Iran. *Journal of Advances in Medicine and Medical Research, 9*(2), 1-11.
<https://doi.org/10.9734/BJMMR/2015/18886>
- Borhani, F., Abbaszadeh, A., & Moosavi, S. (2014). Status of human dignity of adult patients admitted to hospitals of Tehran. *Journal of Medical Ethics and Medical History, 7*(20).
- Bou Khalil, R. (2013). Attitudes, beliefs and perceptions regarding truth disclosure of cancer-related information in the Middle East: a review. *Palliat Support Care, 11*(1), 69-78.
<https://doi.org/10.1017/s1478951512000107>
- Braun, & Clarke. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. <https://doi.org/10.1191/1478088706qp063oa>
- Braun, V., & Clarke, V. (2014). What can "thematic analysis" offer health and wellbeing researchers? *International journal of qualitative studies on health and well-being, 9*, 26152-26152.
<https://doi.org/10.3402/qhw.v9.26152>
- Braun, V., & Clarke, V. (2016). (Mis)conceptualising themes, thematic analysis, and other problems with Fugard and Potts' (2015) sample-size tool for thematic analysis. *International Journal of Social Research Methodology, 19*(6), 739-743. <https://doi.org/10.1080/13645579.2016.1195588>
- Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health, 1*-9. <https://doi.org/10.1080/2159676X.2019.1628806>
- Braun, V., & Clarke, V. (2020). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches [<https://doi.org/10.1002/capr.12360>]. *Counselling and Psychotherapy Research, n/a*(n/a).
<https://doi.org/https://doi.org/10.1002/capr.12360>
- Braun, V., Clarke, V., Hayfield, N., & Terry, G. (2019). Thematic Analysis. In P. Liamputtong (Ed.), *Handbook of Research Methods in Health Social Sciences* (pp. 843-860). Springer Singapore.
https://doi.org/10.1007/978-981-10-5251-4_103
- Bugh, G. R., Ochsenwald, W. L., Barnett, R. D., Maksoud, C. F., Khalaf, S. G., & Kingston, P. (2021). *Lebanon*. Retrieved December 28 from <https://www.britannica.com/place/Lebanon>
- Bunniss, S., & Kelly, D. R. (2010). Research paradigms in medical education research. *Medical Education, 44*(4), 358-366. <https://doi.org/10.1111/j.1365-2923.2009.03611.x>

- Burr, V. (2015). *Social Constructionism* (Third edition ed.). Routledge. <https://doi-org.ezproxy.aub.edu.lb/10.4324/9781315715421>
- Calfat, N. N. (2018). The Frailties of Lebanese Democracy: Outcomes and Limits of the Confessional Framework. *Contexto Internacional*, 40, 269-293.
- Chahine, J. (2003). A very Lebanese fascination with the importance of appearances. *The Daily Star*. <https://www.dailystar.com.lb/News/Lebanon-News/2003/Jul-25/39556-a-very-lebanese-fascination-with-the-importance-of-appearances.ashx>
- Chan, C. L. W., Ho, A. H. Y., Leung, P. P. Y., Chochinov, H. M., Neimeyer, R. A., Pang, S. M. C., & Tse, D. M. W. (2012). The Blessings and the Curses of Filial Piety on Dignity at the End of Life: Lived Experience of Hong Kong Chinese Adult Children Caregivers. *Journal of Ethnic & Cultural Diversity in Social Work*, 21(4), 277-296. <https://doi.org/10.1080/15313204.2012.729177>
- Chaturvedi, S. K., Strohschein, F. J., Saraf, G., & Loiselle, C. G. (2014). Communication in cancer care: psycho-social, interactional, and cultural issues. A general overview and the example of India [10.3389/fpsyg.2014.01332]. *Frontiers in Psychology*, 5, 1332. <https://www.frontiersin.org/article/10.3389/fpsyg.2014.01332>
- Chen, B., & Cammett, M. (2012). Informal politics and inequity of access to health care in Lebanon. *International Journal for Equity in Health*, 11(1), 23. <https://doi.org/10.1186/1475-9276-11-23>
- Cheng, G., & Chen, C. (2021). End-of-Life Needs of Dying Patients and Their Families in Mainland China: A Systematic Review. *OMEGA - Journal of Death and Dying*, 0030222821997340. <https://doi.org/10.1177/0030222821997340>
- Cheraghi, M. A., Manookian, A., & Nasrabadi, A. N. (2014). Human dignity in religion-embedded cross-cultural nursing. *Nursing Ethics*, 21(8), 916-928. <https://doi.org/10.1177/0969733014521095>
- Cheung, A. T. M., & Parent, B. (2021). Mistrust and inconsistency during COVID-19: considerations for resource allocation guidelines that prioritise healthcare workers. *Journal of Medical Ethics*, 47(2), 73. <https://doi.org/10.1136/medethics-2020-106801>
- Chochinov. (2007). Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. *BMJ*, 335(7612), 184. <https://doi.org/10.1136/bmj.39244.650926.47>
- Chochinov, Hack, McClement, Kristjanson, & Harlos. (2002a). Dignity in the terminally ill: a developing empirical model. *Soc Sci Med*, 54. [https://doi.org/10.1016/S0277-9536\(01\)00084-3](https://doi.org/10.1016/S0277-9536(01)00084-3)
- Chochinov, Hack, T., Hassard, T., Kristjanson, L. J., McClement, S., & Harlos, M. (2005). Dignity Therapy: a novel psychotherapeutic intervention for patients near the end of life. *J Clin Oncol*, 23. <https://doi.org/10.1200/JCO.2005.08.391>
- Chochinov, Hack, T., McClement, S., Kristjanson, L., & Harlos, M. (2002b). Dignity in the terminally ill: a developing empirical model. *Social Science & Medicine*, 54(3), 433-443. [https://doi.org/https://doi.org/10.1016/S0277-9536\(01\)00084-3](https://doi.org/https://doi.org/10.1016/S0277-9536(01)00084-3)
- Chochinov, Hassard, T., McClement, S., Hack, T., Kristjanson, L. J., Harlos, M., Sinclair, S., & Murray, A. (2008). The patient dignity inventory: a novel way of measuring dignity-related distress in palliative care. *J Pain Symptom Manage*, 36(6), 559-571. <https://doi.org/10.1016/j.jpainsymman.2007.12.018>
- Chochinov, H., Kristjanson, L., & Hack, T. a. (2006). Dignity in the terminally ill: revisited. . *J Palliat Med*, 9, 666-672.
- Chochinov, H. M. (2002). Dignity-conserving care--a new model for palliative care: helping the patient feel valued. *Jama*, 287(17), 2253-2260. <https://doi.org/10.1001/jama.287.17.2253>
- Chochinov, H. M. (2006). Dying, Dignity, and New Horizons in Palliative End-of-Life Care1 [https://doi.org/10.3322/canjclin.56.2.84]. *CA: A Cancer Journal for Clinicians*, 56(2), 84-103. <https://doi.org/https://doi.org/10.3322/canjclin.56.2.84>
- Chochinov, H. M., Johnston, W., McClement, S. E., Hack, T. F., Dufault, B., Enns, M., Thompson, G., Harlos, M., Damant, R. W., Ramsey, C. D., Davison, S., Zacharias, J., Milke, D., Strang, D.,

- Campbell-Enns, H. J., & Kredentser, M. S. (2016). Dignity and Distress towards the End of Life across Four Non-Cancer Populations. *PLOS ONE*, *11*(1), e0147607.
<https://doi.org/10.1371/journal.pone.0147607>
- Chochinov, H. M., Critjanson, L. J., Breitbart, W., McClement, S., Hack, T., Hassard, T., & Harlos, M. (2011). The effects of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomized controlled trial. *Lancet Oncol*, *12*. [https://doi.org/10.1016/S1470-2045\(11\)70153-X](https://doi.org/10.1016/S1470-2045(11)70153-X)
- Choo, P. Y., Tan-Ho, G., Dutta, O., Patinadan, P. V., & Ho, A. H. Y. . (2019). Reciprocal Dynamics of Dignity in End-of-Life Care: A Multiperspective Systematic Review of Qualitative and Mixed Methods Research. *American Journal of Hospice and Palliative Medicine*.
<https://doi.org/10.1177/1049909119878860>
- CIA World Factbook, a. o. s. (2020). *Lebanon People 2020*. Retrieved April, 14, 2021 from
https://theodora.com/wfbcurrent/lebanon/lebanon_people.html
- Cicero. (1991). *On Duties* ((M.T. Griffin, E.M. Atkins, Trans.) ed.). Cambridge University Press.
- Clark, L., Sanchez Birkhead, A., & Egger, M. J. (2017). A Transcription and Translation Protocol for Sensitive Cross-Cultural Team Research. *Qual Health Res.*, *27*(12), 1751–1764.
<https://doi.org/doi:10.1177/1049732317726761>.
- Clarke, & Braun. (2013a). *Successful qualitative research: A practical guide for beginners*. Sage.
<http://eprints.uwe.ac.uk/21156>
- Clarke, & Braun. (2013b). Teaching thematic analysis [Article]. *Psychologist*, *26*(2), 120-123.
<http://search.ebscohost.com/login.aspx?direct=true&db=asn&AN=87695619&site=ehost-live>
- Clarke, V., & Braun, V. (2014). Thematic Analysis. In *Encyclopedia of Critical Psychology* (pp. 1947-1951). Springer Science. <https://doi.org/DOI 10.1007/978-1-4614-5583-7>
- Clarke, V., & Braun, V. (2017). Thematic analysis. *The Journal of Positive Psychology*, *12*(3), 297-298.
<https://doi.org/10.1080/17439760.2016.1262613>
- Code of Medical Ethics*. (2012). <https://www.aub.edu.lb/fm/shbpp/Documents/New-Code-of-Medical-Ethics-text-ENGLISH-.pdf>
- Cohen, Manion, & Morrison. (2007). *Research Methods in Education* (6th edition ed.). First published 2007 by Routledge.
- Cohen, J., & Ezer, T. (2013). Human rights in patient care: A theoretical and practical framework. *Healths & Human Rights Journal*. <https://www.hhrjournal.org/2013/12/human-rights-in-patient-care-a-theoretical-and-practical-framework/>
- Cottrell, L., & Duggleby, W. (2016). The "good death": An integrative literature review. *Palliat Support Care*, *14*(6), 686-712. <https://doi.org/10.1017/s1478951515001285>
- Council of EU, E. U. (2021). *Syria: Council extends sanctions against the regime for another year*. Retrieved December, 29 from <https://www.consilium.europa.eu/en/press/press-releases/2021/05/27/syria-council-extends-sanctions-against-the-regime-for-another-year/>
- Creswell, J. W. (2009). The Selection of Research Design. In *Research design : qualitative, quantitative, and mixed methods approaches* (3rd ed. ed., pp. 3-21). Sage Publications.
- Cuevas, P. E., Davidson, P., Mejilla, J., & Rodney, T. (2021). Dignity Therapy for End-of-Life Care Patients: A Literature Review. *Journal of Patient Experience*, *8*, 2374373521996951.
<https://doi.org/10.1177/2374373521996951>
- da Silva, M. C. M., Moreira-Almeida, A., & Castro, E. A. B. d. (2018). Elderly caring for the elderly: spirituality as tensions relief [online]. *Revista Brasileira de Enfermagem*, *71*(5), pp. 2461-2468.
<https://doi.org/10.1590/0034-7167-2017-0370>
- Daher, M. (2010). Implementation of Palliative Care in Lebanon. *Journal of Pediatric Hematology/Oncology*, *32*, 43-43.

- Daher, M. (2012). Cultural beliefs and values in cancer patients. *Annals of Oncology*, 23(3).
<https://doi.org/DOI:https://doi.org/10.1093/annonc/mds091>
- Daher, M. (2021, July, 2021). *State of Palliative Care in Lebanon* [Interview].
- Daher, M., & Doumit, M. (2017). Palliative Care in Lebanon: Current Practices, and Perspectives for the Future. In S. M. (Ed.), (Vol. 1, pp. pp. 307-316). Nova Science Publishers, Inc. .
- Daher, M., Estephan, E., Abu-Saad Huijer, H., & Naja, Z. (2008). Implementation of palliative care in Lebanon: past, present, and future. *J Med Liban*, 56(2), 70-76.
- Daher, M., Tabari, H., Stjernswärd, J., Ammar, W., Nabhan, T. A., Khalil, M. B., Dakwar, A., Khoury, M., Lteif, A., Stephan, E., Tueni, E., Makarem, S., Ferris, F. D., Kanazi, G., Tourbah, S. G., Naja, Z., & Mansour, Z. (2002). Lebanon: Pain Relief and Palliative Care. *J Pain Symptom Manage*, 24(2), 200-204. [https://doi.org/10.1016/S0885-3924\(02\)00463-3](https://doi.org/10.1016/S0885-3924(02)00463-3)
- Dakessian Sailian, Salifu, Y., Saad, R., & Preston, N. (2021). Dignity of patients with palliative needs in the Middle East: an integrative review. *BMC Palliat Care*, 20(1), 112.
<https://doi.org/10.1186/s12904-021-00791-6>
- Dakessian Sailian, S., Salifu, Y., Saad, R., & Preston, N. (2021). Dignity of patients with palliative needs in the Middle East: an integrative review. *BMC Palliative Care*, 20(1), 112.
<https://doi.org/10.1186/s12904-021-00791-6>
- Darlaston-Jones, D. (2007). Making connections: The relationship between epistemology and research methods. *The Australian Community Psychologist*, 19(19), 19-27.
- de Graaff, Francke, A. L., van den Muijsenbergh, M. E. T., & van der Geest, S. (2010). 'Palliative care': a contradiction in terms? A qualitative study of cancer patients with a Turkish or Moroccan background, their relatives and care providers. *BMC Palliative Care*, 9, 14p-14p.
<https://doi.org/10.1186/1472-684X-9-19>
- de Voogd, X., Oosterveld-Vlug, M. G., Torensma, M., Onwuteaka-Philipsen, B. D., Willems, D. L., & Suurmond, J. L. (2020). A dignified last phase of life for patients with a migration background: A qualitative study. *Palliative Medicine*, 34(10), 1385-1392.
<https://doi.org/10.1177/0269216320948708>
- de Voogd, X., Willems, D. L., Torensma, M., Onwuteaka-Philipsen, B. D., & Suurmond, J. L. (2021). Dignity of informal caregivers of migrant patients in the last phase of life: a qualitative study. *BMC Palliative Care*, 20(1), 26. <https://doi.org/10.1186/s12904-021-00721-6>
- Dean, R. A. K., & Gregory, D. M. (2004). Humor and laughter in palliative care: An ethnographic investigation. *Palliative & supportive care*, 2(2), 139-148.
<https://doi.org/10.1017/S1478951504040192>
- Devi, S. (2020). *Lebanon Faces a Humanitarian Crisis After the Blast*. www.thelancet.com
- Dewachi, O., Rizk, A., & Singh, N. V. (2018). (Dis)connectivities in wartime: The therapeutic geographies of Iraqi healthcare-seeking in Lebanon. *Glob Public Health*, 13(3), 288-297.
<https://doi.org/10.1080/17441692.2017.1395469>
- Dhiliwal, S. R., & Salins, N. (2015). Smartphone applications in palliative homecare. *Indian J Palliat Care*, 21(1), 88-91. <https://doi.org/10.4103/0973-1075.150199>
- Dodgson, J. E. (2019). Reflexivity in Qualitative Research. *Journal of Human Lactation*, 35(2), 220-222.
<https://doi.org/10.1177/0890334419830990>
- Doumit, M. A., & Abu-Saad, H. H. (2008). Lebanese cancer patients: communication and truth telling preferences. *Contemp Nurse*, 28(1-2), 74-82. <https://doi.org/10.5172/conu.673.28.1-2.74>
- Drabble, L., Trocki, K. F., & Korcha, R. A. (2015). Conducting qualitative interviews by telephone: Lessons learned from a study of alcohol use among sexual minority and heterosexual women. *Qualitative social work : QSW : research and practice*, 1, 118-133.
- Drabble, L., Trocki, K. F., Salcedo, B., Walker, P. C., & Korcha, R. A. (2016). Conducting qualitative interviews by telephone: Lessons learned from a study of alcohol use among sexual minority and

- heterosexual women. *Qualitative social work : QSW : research and practice*, 15(1), 118-133.
<https://doi.org/10.1177/1473325015585613>
- Draucker, C. B., Martsof, D. S., & Poole, C. (2009). Developing Distress Protocols for Research on Sensitive Topics. *Archives of Psychiatric Nursing*, 23(5), 343-350.
<https://doi.org/10.1016/j.apnu.2008.10.008>
- Dumit, N. Y. P. M. A. R. N., & Honein-AbouHaidar, G. P. M. P. H. R. N. (2019). The Impact of the Syrian Refugee Crisis on Nurses and the Healthcare System in Lebanon: A Qualitative Exploratory Study. *Journal of Nursing Scholarship*, 51(3), 289-298.
<https://doi.org/http://dx.doi.org/10.1111/jnu.12479>
- Duthey, B., & Scholten, W. (2014). Adequacy of Opioid Analgesic Consumption at Country, Global, and Regional Levels in 2010, Its Relationship With Development Level, and Changes Compared With 2006. *J Pain Symptom Manage*, 47(2), 283-297.
- Ebrahimi, H., Torabizadeh, C., Mohammadi, E., & Valizadeh, S. (2012). Patients' perception of dignity in Iranian healthcare settings: a qualitative content analysis. *Journal of Medical Ethics*, 38(12), 723.
<https://doi.org/10.1136/medethics-2011-100396>
- ECHR, E. C. o. H. R. (2013). *European Convention on Human Rights*.
https://www.echr.coe.int/documents/convention_eng.pdf
- [Record #8136 is using a reference type undefined in this output style.]
- Egan, R., MacLeod, R., Jaye, C., McGee, R., Baxter, J., Herbison, P., & Wood, S. (2016). Spiritual beliefs, practices, and needs at the end of life: Results from a New Zealand national hospice study. *Palliative and Supportive Care*, 15(2), 223-230. <https://doi.org/10.1017/S147895151600064X>
- El-Jardali, F., & Fadlallah, R. (2017). A review of national policies and strategies to improve quality of health care and patient safety: a case study from Lebanon and Jordan. *BMC Health Services Research*, 17(56). <https://doi.org/DOI 10.1186/s12913-017-2528-1>
- El Nawawi, N. M., Balboni, M. J., & Balboni, T. A. (2012). Palliative care and spiritual care: the crucial role of spiritual care in the care of patients with advanced illness. *Curr Opin Support Palliat Care*, 6(2). https://journals.lww.com/co-supportiveandpalliativecare/Fulltext/2012/06000/Palliative_care_and_spiritual_care_the_crucial.25.aspx
- Elghossain, A., Slim, R., Moubayed, A., & Haboush, J. (2020, March, 21). Special Briefing: Lebanon one year on from the October uprising. *MEI@75*. <https://www.mei.edu/blog/special-briefing-lebanon-one-year-october-uprising>
- Enes. (2003a). An exploration of dignity in palliative care. *Palliat Med*, 17(3), 263-269.
<https://doi.org/10.1191/0269216303pm699oa>
- Enes. (2003b). An exploration of dignity in palliative care. *Palliative Medicine*, 17(3), 263-269.
<https://doi.org/10.1191/0269216303pm699oa>
- Ernst, J., Mehnert, A., Dietz, A., Hornemann, B., & Esser, P. (2017). Perceived stigmatization and its impact on quality of life - results from a large register-based study including breast, colon, prostate and lung cancer patients. *BMC Cancer*, 17(1), 741. <https://doi.org/10.1186/s12885-017-3742-2>
- ESC, T. E. S. C. (2015). *European Social Charter*. <https://www.coe.int/en/web/european-social-charter>
- ESCWA. (2021a). *Launch of the National Strategy for Older Persons in Lebanon 2020 - 2030*.
<https://www.unescwa.org/news/launch-national-strategy-older-persons-lebanon-2020-2030>
- ESCWA. (2021b). *Multidimensional poverty in Lebanon: A proposed measurement framework, and an assessment of the socioeconomic crisis*. Retrieved December 16 from
<https://reliefweb.int/report/lebanon/multidimensional-poverty-lebanon-proposed-measurement-framework-and-assessment>

- Exley, C. (2004). Review article: the sociology of dying, death and bereavement [<https://doi.org/10.1111/j.1467-9566.2004.00382.x>]. *Sociology of Health & Illness*, 26(1), 110-122. <https://doi.org/https://doi.org/10.1111/j.1467-9566.2004.00382.x>
- Fadhil, I., Lyons, G., & Payne, S. (2017). Barriers to, and opportunities for, palliative care development in the Eastern Mediterranean Region. *Lancet Oncol*, 18(3), e176-e184. [https://doi.org/10.1016/s1470-2045\(17\)30101-8](https://doi.org/10.1016/s1470-2045(17)30101-8)
- Farhat, F., Othman, A., El Baba, G., & Kattan, J. (2015). Revealing a cancer diagnosis to patients: attitudes of patients, families, friends, nurses, and physicians in Lebanon-results of a cross-sectional study. *Current oncology (Toronto, Ont.)*, 22(4), e264-e272. <https://doi.org/10.3747/co.22.2351>
- Fearon, D., Kane, H., & Sall, A. (2019). Perceptions of palliative care in a lower middle-income Muslim country: A qualitative study of health care professionals, bereaved families and communities. *Palliative Medicine*, 33(2), 241-249.
- Feghali, J., El Semesmani, H., Abboud, A., Chacra, L., Choucair, K., Fenianos, M., Al Jebbawi, L., El Sayed, F., Kak, F., & Adib, S. M. (2018). Disclosure of Diagnosis and Prognosis to Cancer Patients in Traditional Societies: A Qualitative Assessment from Lebanon. *Journal of Epidemiology and Public Health*, 4(2).
- Feghali, J., El Semesmani, H., Abboud, A., Chacra, L., Choucair, K., Fenianos, M., Al Jebbawi, L., El Sayed, F., Kak, F., & Adib, S. M. (2019). Disclosure of Diagnosis and Prognosis to Cancer Patients in Traditional Societies: A Qualitative Assessment from Lebanon. *Journal of Epidemiology and Public Health*, 4(2), 109-116. <https://doi.org/10.26911/jepublichealth.2019.04.02.06>
- Fernández-Sola, C., Granero-Molina, J., Manrique, G. A., Castro-Sánchez, A. M., Hernández-Padilla, J. M., & Márquez-Membrive, J. (2012). New regulation of the right to a dignified dying in Spain: Repercussions for nursing. *Nursing Ethics*, 19(5), 619–628. <https://doi.org/10.1177/0969733011429016>
- Fink, A. S. (2000). The Role of the Researcher in the Qualitative Research Process. A Potential Barrier to Archiving Qualitative Data. *Forum: Qualitative Social Research*, 1(3). <https://doi.org/DOI:https://doi.org/10.17169/fqs-1.3.1021>
- Folke, C., Biggs, R., Norström, A. V., Reyers, B., & Rockström, J. (2016). Social-ecological resilience and biosphere-based sustainability science. *Ecology and Society*, 21(3), Article 41. <https://doi.org/10.5751/ES-08748-210341>
- Fombuena, M., Galiana, L., Barreto, P., Oliver, A., Pascual, A., & Soto-Rubio, A. (2015). Spirituality in patients with advanced illness: The role of symptom control, resilience and social network. *Journal of Health Psychology*, 21(12), 2765-2774. <https://doi.org/10.1177/1359105315586213>
- Franco, Salvetti MG, Donato SCT, Carvalho RT, & EM., F. (2019). Perception of dignity of patients in palliative care. *Text & Content Nursing*, 28(e20180142). <http://dx.doi.org/10.1590/1980-265X-TCE-2018-0142>
- Fusch, P. I., & Ness, L. R. (2015). Are We There Yet? Data Saturation in Qualitative Research. *The Qualitative Report*, 20(9), 1408-1416. <https://doi.org/10.46743/2160-3715/2015.2281>
- Ghoshal, A., Salins, N., Damani, A., Chowdhury, J., Chitre, A., Muckaden, M. A., Deodhar, J., & Badwe, R. (2019). To Tell or Not to Tell: Exploring the Preferences and Attitudes of Patients and Family Caregivers on Disclosure of a Cancer-Related Diagnosis and Prognosis. *Journal of Global Oncology*(5), 1-12. <https://doi.org/10.1200/JGO.19.00132>
- Ghoshal, A., Salins, N., Damani, A., Chowdhury, J., Chitre, A., Muckaden, M. A., Deodhar, J., & Badwe, R. (2019). To Tell or Not to Tell: Exploring the Preferences and Attitudes of Patients and Family Caregivers on Disclosure of a Cancer-Related Diagnosis and Prognosis. *J Glob Oncol*, 5, 1-12. <https://doi.org/10.1200/jgo.19.00132>

- Gijsberts, M.-J. H. E., Liefbroer, A. I., Otten, R., & Olsman, E. (2019). Spiritual Care in Palliative Care: A Systematic Review of the Recent European Literature. *Medical sciences (Basel, Switzerland)*, 7(2), 25. <https://doi.org/10.3390/medsci7020025>
- Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Methods of data collection in qualitative research: interviews and focus groups. *Bdj*, 204, 291. <https://doi.org/10.1038/bdj.2008.192>
- Gioia, A., & Pitre, E. (1990). Multiparadigm perspectives on Theory Building. *Academy of Management Review*, 15(4), 584-602.
- Given, L. M. (2008). The SAGE Encyclopedia of Qualitative Research Methods. <https://doi.org/10.4135/9781412963909>
- Gogou, P., Tsilika, E., Parpa, E., Kouvaris, I., Damigos, D., Balafouta, M., Maureas, V., & Mystakidou, K. (2015). The Impact of Radiotherapy on Symptoms, Anxiety and QoL in Patients with Cancer. *Anticancer research*, 35, 1771-1775.
- Goldkuhl, G. (2012). Pragmatism vs interpretivism in qualitative information systems research. *European Journal of Information Systems*, 21(2), 135-146. <https://doi.org/http://dx.doi.org/10.1057/ejis.2011.54>
- Gómez-Virseda, C., de Maeseneer, Y., & Gastmans, C. (2019). Relational autonomy: what does it mean and how is it used in end-of-life care? A systematic review of argument-based ethics literature. *BMC Med Ethics*, 20(1), 76. <https://doi.org/10.1186/s12910-019-0417-3>
- Gómez-Virseda, C., de Maeseneer, Y., & Gastmans, C. (2020). Relational autonomy in end-of-life care ethics: a contextualized approach to real-life complexities. *BMC Med Ethics*, 21(1), 50. <https://doi.org/10.1186/s12910-020-00495-1>
- Gott, M., Morgan, T., & Williams, L. (2020). Gender and palliative care: a call to arms. *Palliat Care Soc Pract*, 14, 2632352420957997. <https://doi.org/10.1177/2632352420957997>
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*, 24(2), 105-112. <https://doi.org/10.1016/j.nedt.2003.10.001>
- Greer, S., & Joseph, M. (2015). Palliative Care: A Holistic Discipline. *Integrative Cancer Therapies*, 15(1), 5-9. <https://doi.org/10.1177/1534735415617015>
- Griffin-Heslin, V. L. (2005). An analysis of the concept dignity. *Accid Emerg Nurs*, 13(4), 251-257. <https://doi.org/10.1016/j.aen.2005.09.003>
- Guba, E., & Lincoln, Y. (1994). Competing Paradigms in Qualitative Research. In *Major Paradigms and Perspectives* (pp. 105-117). London Sage.
- Guo, Q., & Jacelon, C. (2014). An integrative review of dignity in end-of-life care. *Palliative Medicine*, 28(7), 931-940. <https://doi.org/10.1177/0269216314528399>
- Gustafson, C., & Lazenby, M. (2019). Assessing the Unique Experiences and Needs of Muslim Oncology Patients Receiving Palliative and End-of-Life Care: An Integrative Review. *Journal of Palliative Care*, 34(1), 52-61. <https://doi.org/10.1177/0825859718800496>
- Hack, T., Chochinov, H., & Hassard, T., et al. . (2004). Defining dignity in terminally ill cancer patients: a factor-analytic approach. . *Psychooncology*, 13, 700–708.
- Hackett, J. (2017). The Importance of Holistic Care at the End of Life. *The Ulster medical journal*, 86(2), 143-144. <https://pubmed.ncbi.nlm.nih.gov/29535491>
- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5846001/>
- Hajjar, R. (2021). The Physician's Role in Running a Palliative Care Service in the Community: The Lebanon Experience. Global Approaches and Future Applications. In S. Michael (Ed.), *Palliative Care for Chronic Cancer Patients in the Community*. Springer.

- Hall, S., Longhurst, S., & Higginson, I. (2009). Living and dying with dignity: a qualitative study of the views of older people in nursing homes. *Age Ageing*, 38(4), 411-416.
<https://doi.org/10.1093/ageing/afp069>
- Hamieh, & Usta. (2011). *The Effects of Socialization on Gender Discrimination and Violence: A Case Study from Lebanon* (OXFAM RESEARCH REPORT, Issue).
- Hammarberg, K., Kirkman, M., & de Lacey, S. (2016). Qualitative research methods: when to use them and how to judge them. *Human Reproduction*, 31(3), 498-501.
<https://doi.org/10.1093/humrep/dev334>
- Hamooleh, M. M., Borimnejad, L., Seyedfatemi, N., & Tahmasebi, M. (2013). Perception of Iranian nurses regarding ethics-based palliative care in cancer patients. *J Med Ethics Hist Med*, 6, 12.
- Harb, I. (2006). Lebanon's Confessionalism: Problems and Prospects.
<https://www.usip.org/publications/2006/03/lebanons-confessionalism-problems-and-prospects>
- Harst de, C. W., Blomberg, K., Benzein, E., &  stlund, U. (2018). Dignity-conserving care actions in palliative care: an integrative review of Swedish research [<https://doi.org/10.1111/scs.12433>]. *Scandinavian Journal of Caring Sciences*, 32(1), 8-23.
<https://doi.org/https://doi.org/10.1111/scs.12433>
- Hasegawa, N., & Ota, K. (2019). Concept synthesis of dignity in care for elderly facility residents. *Nursing Ethics*, 26(7-8), 2016-2034. <https://doi.org/10.1177/0969733018824763>
- Hawker, S., Payne, S., Kerr, C., Hardey, M., & Powell, J. (2002). Appraising the Evidence: Reviewing Disparate Data Systematically. *Qualitative Health Research*, 12(9), 1284-1299.
<https://doi.org/10.1177/1049732302238251>
- Henrich, J., Heine, S. J., & Norenzayan, A. (2010). Most people are not WEIRD. *Nature*, 466(7302), 29-29.
<https://doi.org/10.1038/466029a>
- Henry, L. M., Rushton, C., Beach, M. C., & Faden, R. (2015). Respect and dignity: a conceptual model for patients in the intensive care unit. *Narrat Inq Bioeth*, 5(1a), 5a-14a.
<https://doi.org/10.1353/nib.2015.0007>
- Hernandez, J. G. (2015). Human Value, Dignity, and the Presence of Others. *HEC Forum*(27), 249–263.
<https://doi.org/DOI 10.1007/s10730-015-9271-y>
- Ho, Leung, P. P. Y., Tse, D. M. W., Pang, S. M. C., Chochinov, H. M., Neimeyer, R. A., & Chan, C. L. W. (2013). Dignity Amidst Liminality: Healing Within Suffering Among Chinese Terminal Cancer Patients. *Death Studies*, 37(10), 953-970. <https://doi.org/10.1080/07481187.2012.703078>
- Ho, A., Chan, C., Leung, P., Chochinov, H., Neimeyer, R., Pang, S., & Tse, D. (2013). Living and dying with dignity in Chinese society: Perspectives of older palliative care patients in Hong Kong. *Age and Ageing*, 42. <https://doi.org/10.1093/ageing/aft003>
- Holmerova, I., Juraskova, B., Kalvach, Z., Rohanova, E., Rokosova, M., & Vankova, H. (2007). Dignity and palliative care in dementia. *J Nutr Health Aging*, 11(6), 489-494.
- Hosseini, A., Rezaei, M., Bahrami, M., Abbasi, M., & Hariri, H. (2017). The Relationship between Dignity Status and Quality of Life in Iranian Terminally Ill Patients with Cancer. *Iranian journal of nursing and midwifery research*, 22(3), 178-183. <https://doi.org/10.4103/1735-9066.208157>
- Human Rights Watch. (2021). *Lebanon Events of 2020* (World Report 2021, Issue).
<https://www.hrw.org/world-report/2021/country-chapters/lebanon>
- Hunter, D. J., McCallum, J., & Howes, D. . (2018). Defining Exploratory-Descriptive Qualitative (EDQ) research and considering its application to healthcare. In *Proceedings of Worldwide Nursing Conference 2018 (Worldwide Nursing Conference 2018)*. <http://nursing-conf.org/accepted-papers/#acc-5b9bb119a6443>
- The Inglehart-Welzel World Cultural Map - World Values Survey Source* (2020).
<http://www.worldvaluessurvey.org/>

- Inglehart, R., & Welzel, C. (2005). Modernization, Cultural Change and Democracy: The Human Development Sequence. . In. Cambridge University Press.
- Inglehart, R. F. (2020, December 4). Why is religion suddenly declining? *Academic Insights for the Thinking World*.
- Innes, S., & Payne, S. (2008). Advanced cancer patients' prognostic information preferences: a review. *Palliative Medicine*, 23(1), 29-39. <https://doi.org/10.1177/0269216308098799>
- International Council of Nurses, I. (2021). *The International Code of Ethics for Nurses*. https://www.icn.ch/system/files/2021-10/ICN_Code-of-Ethics_EN_Web_0.pdf
- Isma'eel, H., El Jamal, N., Yazbik Dumit, N., & Al-Chaer, E. (2020, October, 15, 2020). Saving the Suffering Lebanese Healthcare Sector: Immediate Relief while Planning Reforms. *Arab Reform Initiative*. <https://www.arab-reform.net/publication/saving-the-suffering-lebanese-healthcare-sector-immediate-relief-while-planning-reforms/>
- Jacobson, N. (2007). Dignity and health: A review. *Social Science & Medicine*, 64(2), 292-302. <https://doi.org/https://doi.org/10.1016/j.socscimed.2006.08.039>
- Jacobson , N. (2009). Dignity violation in health care. *Qual Health Res*, 19(11), 1536-1547. <https://doi.org/10.1177/1049732309349809>
- Jacobson, N. (2009). A taxonomy of dignity: a grounded theory study. *BMC International Health and Human Rights*, 9(1), 3. <https://doi.org/10.1186/1472-698X-9-3>
- Johnston, B., Papadopoulou, C., Östlund, U., Hunter, K., Andrew, J., & Buchanan, D. (2017). What's Dignity Got To Do With It? Patient Experience of the Dignity Care Intervention: A Qualitative Evaluation Study. *SAGE Open Nursing*, 3, 2377960817699839. <https://doi.org/10.1177/2377960817699839>
- Johnston, B., Pringle, J., Gaffney, M., Narayanasamy, M., McGuire, M., & Buchanan, D. (2015). The dignified approach to care: a pilot study using the patient dignity question as an intervention to enhance dignity and person-centred care for people with palliative care needs in the acute hospital setting. *BMC Palliat Care*, 14, 9. <https://doi.org/10.1186/s12904-015-0013-3>
- Johnston, B., & Smith, L. N. (2006). Nurses' and patients' perceptions of expert palliative nursing care. *J Adv Nurs*, 54(6), 700-709. <https://doi.org/10.1111/j.1365-2648.2006.03857.x>
- Joseph, S. (2011). Political Familism in Lebanon. *The Annals of the American Academy of Political and Social Science*, 636, 150-163. <http://www.jstor.org.ezproxy.aub.edu.lb/stable/41328556>
- Kadivar, M., Hamooleh, M. M., & Kouhnavard, M. (2018). Concept analysis of human dignity in patient care: Rodgers' evolutionary approach. *Journal of Medical Ethics and History of Medicine*, 11(0). <https://jmehm.tums.ac.ir/index.php/jmehm/article/view/320>
- Kalu, F. A., & Bwalya, J. C. . (2017). What Makes Qualitative Research Good Research? An Exploratory Analysis of Critical Elements. . *International Journal of Social Science Research*, 5(2), 43-56. <https://doi.org/10.5296/ijssr.v5i2.10711>
- Kang, N. E., Kim, H. Y., Kim, J. Y., & Kim, S. R. (2020). Relationship between cancer stigma, social support, coping strategies and psychosocial adjustment among breast cancer survivors [<https://doi.org/10.1111/jocn.15475>]. *Journal of Clinical Nursing*, 29(21-22), 4368-4378. <https://doi.org/https://doi.org/10.1111/jocn.15475>
- Kant, I. (1981). *Grounding for the metaphysic of morals* (t. (J.W. Ellington, Ed.).
- Kattan, C., Badreddine, H., Rassy, E., Kourie, H. R., & Kattan, J. (2020). The impact of the coronavirus pandemic on the management of cancer patients in Lebanon: a single institutional experience. *Future oncology (London, England)*, 16(17), 1157-1160. <https://doi.org/10.2217/fo-2020-0313>
- Kellehear, A. (2013). Compassionate communities: end-of-life care as everyone's responsibility. *QJM: An International Journal of Medicine*, 106(12), 1071-1075. <https://doi.org/10.1093/qjmed/hct200>
- Kennedy, G. (2016). The Importance of Patient Dignity in Care at the End of Life. *The Ulster medical journal*, 85(1), 45-48. <https://pubmed.ncbi.nlm.nih.gov/27158166>

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4847835/>

[Record #9141 is using a reference type undefined in this output style.]

- Khalil, R. B. (2012). Attitudes, beliefs and perceptions regarding truth disclosure of cancer-related information in the Middle East: A review. *Palliative and Supportive Care*, 11(1), 69-78. <https://doi.org/10.1017/S1478951512000107>
- Kiger, M. E., & Varpio, L. (2020). Thematic analysis of qualitative data: AMEE Guide No. 131. *Medical Teacher*. [https://doi.org/DOI: 10.1080/0142159X.2020.1755030](https://doi.org/DOI:10.1080/0142159X.2020.1755030)
- King, N. (2004). Using Interviews in Qualitative Research in Organizational Research. In *Essential Guide to Qualitative Methods* (pp. 11-22). Sage.
- Kivunja, C., & Kuyini, A. B. (2017). Understanding and Applying Research Paradigms in Educational Contexts. *International Journal of Higher Education*, 6(5), 26-41. <https://doi.org/https://doi.org/10.5430/ijhe.v6n5p26>
- Knapp, S., Marziliano, A., & Moyer, A. (2014). Identity threat and stigma in cancer patients. *Health psychology open*, 1(1), 2055102914552281-2055102914552281. <https://doi.org/10.1177/2055102914552281>
- Knoema. (2020). *Lebanon-number of death*. Retrieved December, 29 from <https://knoema.com/atlas/Lebanon/topics/Demographics/Mortality/Number-of-deaths>
- Kolmar, A., Jordan, M., Amy Lee, Y.-L., Turner, D., & Kamal, A. (2019). 416: A SYSTEMATIC REVIEW OF PROVIDER EXPERIENCES WITH PALLIATIVE CARE IN MUSLIM PATIENT POPULATIONS. *Critical Care Medicine*, 47, 189-189. <https://doi.org/10.1097/01.ccm.0000551169.37983.0d>
- Korhan, E. A., Üstün, Ç., & Yilmaz, D. U. (2018). Practices in Human Dignity in Palliative Care: A Qualitative Study. *Holistic Nursing Practice*, 32(2), 71-80. <https://doi.org/10.1097/HNP.0000000000000252>
- Korstjens, I., & Moser, A. (2018). Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *European Journal of General Practice*, 24(1), 120-124. <https://doi.org/10.1080/13814788.2017.1375092>
- Kronfol. (2006). Rebuilding of the Lebanese health care system: health sector reforms. *Eastern Mediterranean Health Journal*, 12(Nos 3/4), 459-473.
- Lai, D. W. L., & Surood, S. (2009). FILIAL PIETY IN CHINESE CANADIAN FAMILY CAREGIVERS. *International Journal of Sociology of the Family*, 35(1), 89-104. <http://www.jstor.org/stable/23028802>
- Lancet, T. (2018). Why talking about dying matters. *The Lancet*, 392(10157), 1488. [https://doi.org/DOI:https://doi.org/10.1016/S0140-6736\(18\)32546-7](https://doi.org/DOI:https://doi.org/10.1016/S0140-6736(18)32546-7)
- Landry, M. D., Alameddine, M., Jesus, T. S., Sassine, S., Koueik, E., & Raman, S. R. (2020). The 2020 blast in the Port of Beirut: can the Lebanese health system “build back better”? *BMC Health Services Research*, 20(1), 1040. <https://doi.org/10.1186/s12913-020-05906-y>
- Langdon, E. J., & Wiik, F. B. (2010). Anthropology, Health and Illness: an Introduction to the Concept of Culture Applied to the Health Sciences. *Rev. Latino-Am. Enfermagem*, 18(3), 459-466. www.eerp.usp.br/rlae
- Larkin, P. J., Dierckx de Casterlé, B., & Schotsmans, P. (2007). Multilingual translation issues in qualitative research: reflections on a metaphorical process. *Qual Health Res*, 17(4), 468-476. <https://doi.org/10.1177/1049732307299258>
- Lau, B. H.-P., Wong, D. F. K., Fung, Y. L., Zhou, J., Chan, C. L. W., & Chow, A. Y. M. (2018). Facing death alone or together? Investigating the interdependence of death anxiety, dysfunctional attitudes, and quality of life in patient-caregiver dyads confronting lung cancer [<https://doi.org/10.1002/pon.4773>]. *Psycho-Oncology*, 27(8), 2045-2051. <https://doi.org/https://doi.org/10.1002/pon.4773>
- Lerberghe, W. V., Mechbal, A., & Kronfol, N. (2018). *THE COLLABORATIVE GOVERNANCE OF LEBANON'S HEALTH SECTOR: TWENTY YEARS OF EFFORTS TO TRANSFORM HEALTH SYSTEM PERFORMANCE*.

<https://moph.gov.lb/userfiles/files/Programs%26Projects/PSO/The-Collaborative-Governance-of-Lebanons-Health-Sector.pdf>

- Lewis, S., Broom, A., Kenny, K., & Kirby, E. (2020). Cancer caregivers' experiences of prognosis in Australia: a qualitative interview study. *BMJ Open*, *10*(1), e032361. <https://doi.org/10.1136/bmjopen-2019-032361>
- Li, H. C., Richardson, A., Speck, P., & Armes, J. (2014). Conceptualizations of dignity at the end of life: exploring theoretical and cultural congruence with dignity therapy. *J Adv Nurs*, *70*(12), 2920-2931. <https://doi.org/10.1111/jan.12455>
- Lin, Y.-P., Watson, R., & Tsai, Y.-F. (2012). Dignity in care in the clinical setting: A narrative review. *Nursing Ethics*, *20*(2), 168-177. <https://doi.org/10.1177/0969733012458609>
- López-Sierra, H. E., & Rodríguez-Sánchez, J. (2015). The supportive roles of religion and spirituality in end-of-life and palliative care of patients with cancer in a culturally diverse context: a literature review. *Curr Opin Support Palliat Care*, *9*(1), 87-95. <https://doi.org/10.1097/spc.000000000000119>
- Lorentsen, V. B., Nåden, D., & Sæteren, B. (2019). The meaning of dignity when the patients' bodies are falling apart. *Nursing open*, *6*(3), 1163-1170. <https://doi.org/10.1002/nop2.301>
- Lou, C., Lou, K., & Ridley, J. (2020). Exploring the meaning of dignity at end of life for Chinese Canadians caregivers: A qualitative cross-cultural study. *Palliative Medicine*, *35*(1), 142-150. <https://doi.org/10.1177/0269216320956809>
- Lynch, T. P., Connor, S. P., & Clark, D. P. (2013). Mapping Levels of Palliative Care Development: A Global Update. *J Pain Symptom Manage*, *45*(6), 1094-1106. <https://doi.org/10.1016/j.jpainsymman.2012.05.011>
- Mackenzie, N., & Knipe, S. (2006). Research dilemmas: paradigms, methods and methodology. *Issues In Educational Research & Theory for Nursing Practice*, *16*, 1-15.
- Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qual Health Res*, *26*(13), 1753-1760. <https://doi.org/10.1177/1049732315617444>
- Manookian, A., Cheraghi, M. A., & Nasrabadi, A. N. (2013). Factors influencing patients' dignity: A qualitative study. *Nursing Ethics*, *21*(3), 323-334. <https://doi.org/10.1177/0969733013498526>
- Manookian, A., Cheraghi, M. A., & Nasrabadi, A. N. (2014). Factors influencing patients' dignity: A qualitative study. *Nurs Ethics*, *21*(3), 323-334. <https://doi.org/10.1177/0969733013498526>
- Martínez, M., Arantzamendi, M., Belar, A., Carrasco, J. M., Carvajal, A., Rullán, M., & Centeno, C. (2017). 'Dignity therapy', a promising intervention in palliative care: A comprehensive systematic literature review. *Palliat Med*, *31*(6), 492-509. <https://doi.org/10.1177/0269216316665562>
- Marvin, L. (2015). A New Approach to the Ethics of Life: The "Will to Live" in Liew of Inherent Dignity or Autonomy-Based Approaches. *Southern California Interdisciplinary Law Journal*, *24*, 27-805.
- Mattson, D. J., & Clark, S. G. (2011). Human dignity in concept and practice. *Policy Sciences*, *44*(4), 303-319. <http://www.jstor.org/stable/41486845>
- Mays, N., Pope, C., & Popay, J. (2005). Systematically reviewing qualitative and quantitative evidence to inform management and policy-making in the health field. *Journal of Health Services Research & Policy*, *10*(1_suppl), 6-20. <https://doi.org/10.1258/1355819054308576>
- McIlpatrick, Connolly, M., Collins, R., Murphy, T., Johnston, B., & Larkin, P. (2017). Evaluating a dignity care intervention for palliative care in the community setting: community nurses' perspectives. *J Clin Nurs*, *26*(23-24), 4300-4312. <https://doi.org/10.1111/jocn.13757>
- McIlpatrick, S., Connolly, M., Collins, R., Murphy, T., Johnston, B., & Larkin, P. (2017). Evaluating a dignity care intervention for palliative care in the community setting: community nurses' perspectives

- [\[https://doi.org/10.1111/jocn.13757\]](https://doi.org/10.1111/jocn.13757). *Journal of Clinical Nursing*, 26(23-24), 4300-4312.
<https://doi.org/https://doi.org/10.1111/jocn.13757>
- Mealer, M., & Jones, J. R. (2014). Methodological and ethical issues related to qualitative telephone interviews on sensitive topics. *Nurse Res*, 21(4), 32-37.
<https://doi.org/10.7748/nr2014.03.21.4.32.e1229>
- Mehdipour-Rabori, R., Abbaszadeh, A., & Borhani, F. (2016). Human dignity of patients with cardiovascular disease admitted to hospitals of Kerman, Iran, in 2015 *Journal of Medical Ethics and History of Medicine*, 9(8).
- Merriam-Webster online. (2018, December, 12, 2018). *Dignity Definition #2*. Retrieved December, 19 from <https://www.merriam-webster.com/dictionary/dignity>
- Patients Rights, Pub. L. No. 574, Ministry of Public Health (2004).
<https://www.moph.gov.lb/en/Pages/11/2621/patients-rights>
- Mouhaweij, M. C., Maalouf-Haddad, N., & Tohmé, A. (2017). Cultural Challenges in Implementing Palliative Services in Lebanon. *Palliative Medicine & Hospice Care*, SE(1), S15-S18.
<https://doi.org/doi:10.17140/PMHCOJ-SE-1-104>
- MSF, M. S. F. (2021). *Supply shortages and economic instability are decimating Lebanon's health care system*. OCHA Retrieved December 16 from
- Muckaden, M., Dighe, M., Balaji, P., Dhiliwal, S., Tilve, P., Jadhav, S., & Goswami, S. (2011). Paediatric palliative care: theory to practice. *Indian Journal of Palliative Care*, 17(Suppl), S52-S60.
<https://doi.org/10.4103/0973-1075.76244>
- Munthe-Kaas, H. M., Glenton, C., Booth, A., Noyes, J., & Lewin, S. (2019). Systematic mapping of existing tools to appraise methodological strengths and limitations of qualitative research: first stage in the development of the CAMELOT tool. *BMC Medical Research Methodology*, 19(1), 113.
<https://doi.org/10.1186/s12874-019-0728-6>
- Naderifar, M., Goli, H., & Ghaljaie, F. (2017). Snowball Sampling: A Purposeful Method of Sampling in Qualitative Research. *trides in Development of Medical Education*, 14(3). <https://doi.org/doi:10.5812/sdme.67670>.
- Nathan, S., Newman, C., & Lancaster, K. (2019). Qualitative Interviewing. In *Handbook of Research Methods in Health Social Sciences* (pp. 391- 410). Springer Nature Singapore Pte Ltd.
https://doi.org/10.1007/978-981-10-5251-4_77
- National Institute For Health & Care Excellence, N. (2017). NICE guideline: Carers: provision of support for adult carers draft scope for consultation.
<https://www.nice.org.uk/guidance/ng150/documents/draft-scope>
- Newman, D. S., & Clare, M. M. (2016). School Psychology as a Relational Enterprise: the Role and Process of Qualitative Methodology. *Contemporary School Psychology*, 20(4), 327-335.
<https://doi.org/10.1007/s40688-016-0090-1>
- Novick, G. (2008). Is There a Bias Against Telephone Interviews In Qualitative Research? *Research in nursing & health*, 31, 391-398. <https://doi.org/10.1002/nur.20259>
- Ochuko, R. (2021). *4 Simple Love Gestures That Drive Men Crazy*. The Guardian. Retrieved September 5 from <https://guardian.ng/life/4-simple-love-gestures-that-drive-men-crazy/>
- Ohlson, M. (2020). Effects of Socioeconomic Status and Race on Access to Healthcare in the United States. *Perspectives*, 12. <https://scholars.unh.edu/perspectives/vol12/iss1/2>
- Olteanu, A. (2019). Cultural Relativism and Politics of Recognition. In A. Olteanu (Ed.), *Multiculturalism as Multimodal Communication: A Semiotic Perspective* (pp. 33-54). Springer International Publishing. https://doi.org/10.1007/978-3-030-17883-3_2
- Osman. (2015). Development of palliative care in Lebanon: Obstacles and opportunities [Article]. *Journal Medical Libanais*, 63(1), 42-46.
<http://www.embase.com/search/results?subaction=viewrecord&from=export&id=L605222459>

- Osman, Rihan, A., Garralda, E., Rhee, J., José Pons, J., De Lima, L., Tfayli, A., & Centeno, C. (2017). *Atlas of Palliative Care in the Eastern Mediterranean Region*. IAHPC Press.
- Östlund, U., Blomberg, K., Söderman, A., & Werkander Harstäde, C. (2019). How to conserve dignity in palliative care: suggestions from older patients, significant others, and healthcare professionals in Swedish municipal care. *BMC Palliat Care*, 18(1), 10. <https://doi.org/10.1186/s12904-019-0393-x>
- Ostlund, U., Brown, H., & Johnston, B. (2012). Dignity conserving care at end-of-life: a narrative review. *Eur J Oncol Nurs*, 16(4), 353-367. <https://doi.org/10.1016/j.ejon.2011.07.010>
- Oystacher, T., Blasco, D., He, E., Huang, D., Schear, R., McGoldrick, D., Link, B., & Yang, L. (2018a). Understanding stigma as a barrier to accessing cancer treatment in South Africa: Implications for public health campaigns. *Pan African Medical Journal*, 29. <https://doi.org/10.11604/pamj.2018.29.73.14399>
- Oystacher, T., Blasco, D., He, E., Huang, D., Schear, R., McGoldrick, D., Link, B., & Yang, L. H. (2018b). Understanding stigma as a barrier to accessing cancer treatment in South Africa: implications for public health campaigns. *The Pan African medical journal*, 29, 73-73. <https://doi.org/10.11604/pamj.2018.29.73.14399>
- Palfrey, H., Armour, K., Grubb, R., & Ives, J. (2016). How should compassion be conceived and enacted in end of life care? A patient perspective. *BMJ Supportive & Palliative Care*, 6(3), 401. <https://doi.org/10.1136/bmjspcare-2016-001204.44>
- Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Administration and policy in mental health*, 42(5), 533-544. <https://doi.org/10.1007/s10488-013-0528-y>
- Pan, Y., Chen, R., & Yang, D. (2022). The relationship between filial piety and caregiver burden among adult children: A systematic review and meta-analysis. *Geriatric Nursing*, 43, 113-123. <https://doi.org/https://doi.org/10.1016/j.gerinurse.2021.10.024>
- Paulson, D. S. (2004). Taking Care of Patients and Caring for Patients Are Not the Same. *AORN Journal*, 79(2), 359-366. [https://doi.org/https://doi.org/10.1016/S0001-2092\(06\)60612-1](https://doi.org/https://doi.org/10.1016/S0001-2092(06)60612-1)
- Phelan, S. M., Griffin, J. M., Jackson, G. L., Zafar, S. Y., Hellerstedt, W., Stahre, M., Nelson, D., Zullig, L. L., Burgess, D. J., & van Ryn, M. (2013). Stigma, perceived blame, self-blame, and depressive symptoms in men with colorectal cancer. *Psychooncology*, 22(1), 65-73. <https://doi.org/10.1002/pon.2048>
- Pleschberger, S. (2007). Dignity and the challenge of dying in nursing homes: the residents' view. *Age Ageing*, 36(2), 197-202. <https://doi.org/10.1093/ageing/af1152>
- Radbruch, L., De Lima, L., Knaul, F., Wenk, R., Zipporah Ali, Bhatnagar, S., Blanchard, C., Bruera, E., Buitrago, R., Burla, C., Callaway, M., Munyoro, E. C., Centeno, C., Cleary, J., Connor, S., Davaasuren, O., Downing, J., & Foley, K. (2020). Redefining Palliative Care—A New Consensus-Based Definition. *Journal of Pain & Symptom Management*, 60(4), 754-764. [https://www.jpmsjournal.com/article/S0885-3924\(20\)30247-5/fulltext](https://www.jpmsjournal.com/article/S0885-3924(20)30247-5/fulltext)
- Ranganathan, A., Gunnarsson, O., & Casarett, D. (2014). Palliative care and advance care planning for patients with advanced malignancies. *Ann Palliat Med*, 3(3), 144-149. <https://doi.org/10.3978/j.issn.2224-5820.2014.07.04>
- Reid, M., Ghesquiere, A., Kenien, C., Capezuti, E., & Gardner, D. (2017). Expanding palliative care's reach in the community via the elder service agency network. *Annals of Palliative Medicine; Vol 7, Supplement 3 (October 2018): Annals of Palliative Medicine (Outcome Measurement for Advanced Disease Patients)*, 6(1), S104-S107. Retrieved from <https://apm.amegroups.com/article/view/14441>

- Rejnö, Å., Ternestedt, B.-M., Nordenfelt, L., Silfverberg, G., & Godskesen, T. E. (2019). Dignity at stake: Caring for persons with impaired autonomy. *Nursing Ethics*, 27(1), 104-115.
<https://doi.org/10.1177/0969733019845128>
- Rida, M. A., & Zeineldine, S. (2013). Palliative Care in Lebanon: The Law and the Patient. *Lebanese Medical Journal*, 61 (4), 237-239.
- Ridic, G., Gleason, S., & Ridic, O. (2012). Comparisons of health care systems in the United States, Germany and Canada. *Materia socio-medica*, 24(2), 112-120.
<https://doi.org/10.5455/msm.2012.24.112-120>
- Ritchie, J., Lewis, J., McNaughton, N. C., & Ormston, R. (2013). The Foundations of Qualitative Research. In *Qualitative Research Practice. A Guide for Social Science Students and Researchers* (pp. 1-25). Sage.
- Rodríguez-Prat, A., Monforte-Royo, C., Porta-Sales, J., Escribano, X., & Balaguer, A. (2016). Patient Perspectives of Dignity, Autonomy and Control at the End of Life: Systematic Review and Meta-Ethnography. *PLOS ONE*, 11(3), e0151435-e0151435.
<https://doi.org/10.1371/journal.pone.0151435>
- Rodríguez-Prat, A., Monforte-Royo, C., Porta-Sales, J., Escribano, X., & Balaguer, A. (2016). Patient Perspectives of Dignity, Autonomy and Control at the End of Life: Systematic Review and Meta-Ethnography. *PLoS One*, 11(3), e0151435. <https://doi.org/10.1371/journal.pone.0151435>
- Rosenberg, J. (2011). Whose Business is Dying? Death, the Home and Palliative Care. *Cultural Studies Review*, 17(1), 15-30.
<http://proquest.umi.com/login/athens?url=https://www.proquest.com/scholarly-journals/whose-business-is-dying-death-home-palliative/docview/874498526/se-2>
https://oneresearch.lancaster-university.uk/openurl/44LAN/44LAN_services_page?url_ver=Z39.88-2004&rft_val_fmt=info:ofi/fmt:kev:mtx:journal&genre=article&sid=ProQ:ProQ%3Aartshumanities&atitle=Whose+Business+is+Dying%3F+Death%2C+the+Home+and+Palliative+Care&title=Cultural+Studies+Review&issn=14468123&date=2011-03-01&volume=17&issue=1&spage=15&au=Rosenberg%2C+John&isbn=&jtitle=Cultural+Studies+Review&bttitle=&rft_id=info:eric/&rft_id=info:doi/
- Sadler, G. R., Lee, H.-C., Lim, R. S.-H., & Fullerton, J. (2010). Research Article: Recruitment of hard-to-reach population subgroups via adaptations of the snowball sampling strategy [<https://doi.org/10.1111/j.1442-2018.2010.00541.x>]. *Nursing & Health Sciences*, 12(3), 369-374.
<https://doi.org/https://doi.org/10.1111/j.1442-2018.2010.00541.x>
- Salifu, Y., Almack, K., & Caswell, G. (2020). 'My wife is my doctor at home': A qualitative study exploring the challenges of home-based palliative care in a resource-poor setting. *Palliative Medicine*, 35(1), 97-108. <https://doi.org/10.1177/0269216320951107>
- Salins, N., Ghoshal, A., Hughes, S., & Preston, N. (2020). How views of oncologists and haematologists impacts palliative care referral: a systematic review. *BMC Palliative Care*, 19(1), 175.
<https://doi.org/10.1186/s12904-020-00671-5>
- Sallnow, L., Kumar, S., & Kellehear, A. (2012). *International perspectives on public health and palliative care*. Routledge Abingdon.
- Sallnow, L., Smith, R., Ahmedzai, S. H., Bhadelia, A., Chamberlain, C., Cong, Y., Doble, B., Dullie, L., Durie, R., Finkelstein, E. A., Guglani, S., Hodson, M., Husebø, B. S., Kellehear, A., Kitzinger, C., Knaul, F. M., Murray, S. A., Neuberger, J., O'Mahony, S., Rajagopal, M. R., ussell, S. R., Sase, E., Sleeman, K. E., Solomon, S., Taylor, R. M. T., van Furth, & Wyatt, K. (2022). Report of the Lancet Commission on the Value of Death: bringing death back into life. *The Lancet*, E 399(10327), P837-884. [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(21\)02314-X/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)02314-X/fulltext)

- Saxena, S., & Hanna, F. (2015). Dignity--a fundamental principle of mental health care. *The Indian journal of medical research*, 142(4), 355-358. <https://doi.org/10.4103/0971-5916.169184>
- Schroeder, & Bani-Sadr. (2017). Middle East and West: Can Common Ground Be Found? In *Dignity in the 21st Century: Middle East and West* (pp. 89-97). Springer.
- Schroeder, D., & Bani-Sadr, B. (2017). The Quest for Dignity. In *Dignity in the 21st Century Middle East and West* (pp. 1-8). Springer Open. <https://doi.org/10.1007/978-3-319-58020-3>
- Schuit, A. S., Holtmaat, K., van Zwieten, V., Aukema, E. J., Gransier, L., Cuijpers, P., & Verdonck-de Leeuw, I. M. (2021). Organizing Psycho-Oncological Care for Cancer Patients: The Patient's Perspective. *Front Psychol*, 12, 625117. <https://doi.org/10.3389/fpsyg.2021.625117>
- Sen, K., & Mehio-Sibai, A. (2004). TRANSNATIONAL CAPITAL AND CONFESSIONAL POLITICS: THE PARADOX OF THE HEALTH CARE SYSTEM IN LEBANON. *International Journal of Health Services*, 34(3), 527-551. <http://www.jstor.org.ezproxy.aub.edu.lb/stable/45132225>
- Shahhoseini, S., Borhani, F., Atashzadeh Shoorideh, F., Kavousi, A., Bagheri, H., & Almasi-Hashiani, A. (2017). Different Sources of Dignity-Related Distress in Women Receiving Chemotherapy for Breast Cancer. *Asian Pac J Cancer Prev*, 18(11), 2953-2958. <https://doi.org/10.22034/APJCP.2017.18.11.2953>
- Shallal, A., Lahoud, C., Zervos, M., & Matar, M. (2021). Lebanon is losing its frontline. *J Glob Health*, 11.
- Sharifi, S., Borhani, F., & Abbaszadeh, A. (2016). Factors affecting dignity of patients with multiple sclerosis. *Scand J Caring Sci*, 30(4), 731-740. <https://doi.org/10.1111/scs.12299>
- Silbermann, M., Arnaout, M., Daher, M., Nestoros, S., Pitsillides, B., Charalambous, H., Gultekin, M., Fahmi, R., Mostafa, K. A. H., Khleif, A. D., Manasrah, N., & Oberman, A. (2012). Palliative cancer care in Middle Eastern countries: accomplishments and challenges. *Annals of oncology : official journal of the European Society for Medical Oncology*, 23 Suppl 3(Suppl 3), 15-28. <https://doi.org/10.1093/annonc/mds084>
- Silbermann, M., Fink, R. M., Min, S. J., Mancuso, M. P., Brant, J., Hajjar, R., Al-Alfi, N., Baider, L., Turker, I., ElShamy, K., Ghayeb, I., Al-Jadiry, M., Khader, K., Kav, S., Charalambous, H., Uslu, R., Kebudi, R., Barsela, G., Kuruku, N., Mutafoglu, K., Ozalp-Senel, G., Oberman, A., Kislev, L., Khleif, M., Keoppi, N., Nestoros, S., Abdalla, R. F., Rassouli, M., Morag, A., Sabar, R., Nimri, O., Al-Qadire, M., Al-Khalaileh, M., Tayyem, M., Doumit, M., Punjwani, R., Rasheed, O., Fallatah, F., Can, G., Ahmed, J., & Strode, D. (2015). Evaluating palliative care needs in Middle Eastern countries. *J Palliat Med*, 18(1), 18-25. <https://doi.org/10.1089/jpm.2014.0194>
- Sindhu, F., & Dickson, R. (1997). The complexity of searching the literature. *Int J Nurs Pract*, 3(4), 211-217. <https://doi.org/10.1111/j.1440-172X.1997.tb00104.x>
- Smith, H. J., Chen, J., & Liu, X. (2008). Language and rigour in qualitative research: Problems and principles in analyzing data collected in Mandarin. *BMC Medical Research Methodology*, 8(1), 44. <https://doi.org/10.1186/1471-2288-8-44>
- Sotiriadou, P., Brouwers, J., & Le, T.-A. (2014). Choosing a qualitative data analysis tool: a comparison of NVivo and Leximancer. *Annals of Leisure Research*, 17(2), 218-234. <https://doi.org/10.1080/11745398.2014.902292>
- Soueidan, Osman H, & F, E.-J. (2018). *K2P Policy Brief: Integrating Palliative Care into the Health System in Lebanon*. (Knowledge to Policy (K2P) Center, Issue.
- Staats, K., Grov, E. K., Husebø, B. S., & Tranvåg, O. (2020). Dignity and loss of dignity: Experiences of older women living with incurable cancer at home. *Health Care for Women International*, 41(9), 1036-1058. <https://doi.org/10.1080/07399332.2020.1797035>
- Stanton, K. M. (2021). *Lotus Flower Meanings & Symbolism + Planting, Care & Uses*. Retrieved December 13 from
- Stead, G. B. (2004). Culture and career psychology: A social constructionist perspective. *Journal of Vocational Behavior*, 64, 389-406.

- Stein Messetti, P. A., & de Abreu Dallari, D. (2018). Human dignity in the light of the Constitution, human rights and bioethics. *28, 3*, 283–289. <https://doi-org.ezproxy.aub.edu.lb/10.7322/jhgd.152176>
- Stolberg, M. (2014). Metaphors and Images of Cancer in Early Modern Europe. *Bulletin of the History of Medicine*, *88*(1), 48-74. <https://www.jstor.org/stable/26308891>
- Sychev, A. A. (2017). Evolution of The Concept of Dignity in The History of Ethics *RUDN Journal Of Philosophy*, *21*(3), 305-313. <https://doi.org/doi:10.22363/2313-2302-2017-21-3-305-313>
- Tan-Ho, G., Choo, P. Y., Patinadan, P. V., Low, C. X., & Ho, A. H. Y. (2020). Blessings or burdens: an Interpretative Phenomenological Analysis (IPA) study on the motivations and their impact on end-of-life caregiving among Asian family caregivers. *BMC Palliative Care*, *19*(1), 132-132. <https://doi.org/10.1186/s12904-020-00638-6>
- Taylor, A. K., Armitage, S., & Kausar, A. (2021). A challenge in qualitative research: Family members sitting in on interviews about sensitive subjects. *Health expectations : an international journal of public participation in health care and health policy*, *24*(4), 1545-1546. <https://doi.org/10.1111/hex.13263>
- Tehrani, T. H., Seyed Bagher Maddah, S., Fallahi-Khoshknab, M., Ebadi, A., Mohammadi Shahboulaghi, F., & Gillespie, M. (2018). Respecting the privacy of hospitalized patients: An integrative review. *Nursing Ethics*, 0969733018759832. <https://doi.org/10.1177/0969733018759832>
- Temraz, S., Salim Hammoud, M., Saleh, A., Charafeddine, M., Mukherji, D., & Shamseddine, A. (2019). Perceptions of Cancer Status Disclosure in Lebanon. *J Cancer Educ*, *34*(5), 874-881. <https://doi.org/10.1007/s13187-018-1389-6>
- Teti, M., Schatz, E., & Liebenberg, L. (2020). Methods in the Time of COVID-19: The Vital Role of Qualitative Inquiries. *International Journal of Qualitative Methods*, *19*, 1609406920920962. <https://doi.org/10.1177/1609406920920962>
- The Lancet. (2020). Palliative care and the COVID-19 pandemic. *Lancet (London, England)*, *395*(10231), 1168-1168. [https://doi.org/10.1016/S0140-6736\(20\)30822-9](https://doi.org/10.1016/S0140-6736(20)30822-9)
- The New Humanitarian. (2008). *Patients suffer privatised, politicised healthcare*. IRIN News. Retrieved November, 4, 2021 from <https://www.thenewhumanitarian.org/report/77000/lebanon-patients-suffer-privatised-politicised-healthcare>
- The United Nations General Assembly. (2019). *Political Declaration of the High-level Meeting on Universal Health Coverage “Universal health coverage: moving together to build a healthier world”* (Global health and foreign policy, Issue. <https://www.un.org/pga/73/event/universal-health-coverage/>
- The World Bank. (2020, May,2, 2020). *Islamic Republic of Iran*. <https://www.worldbank.org/en/country/iran/overview>
- The World Medical Association. (2018). *WMA International Code of Medical Ethics*. Retrieved May,4, 2020 from
- Thomas, D. R. (2006). A General Inductive Approach for Analyzing Qualitative Evaluation Data. *American Journal of Evaluation*, *27*(2), 237-246. <https://doi.org/10.1177/1098214005283748>
- Tieman, J., Sladek, R., & Currow, D. (2009). Multiple sources: mapping the literature of palliative care. *Palliative Medicine*, *23*, 425–431. <https://doi.org/10.1177/0269216309102727>
- Tollow, P., Ogden, J., McCabe, C. S., & Harcourt, D. (2020). 'Physical appearance and well-being in adults with incurable cancer: a thematic analysis'. *BMJ Support Palliat Care*. <https://doi.org/10.1136/bmjspcare-2020-002632>
- Toom, K., & Miller, P. F. (2017). Ethics and Integrity. In *Research Management : Europe and Beyond* (pp. 264-286). Elsevier Science & Technology.
- Torres, M. B., & Rao, N. (2007). Disclosure and Truth in Physician–Patient Communication An Exploratory Analysis in Argentina, Brazil, India and the United States. *Journal of Creative Communications*, *2*(3), 279-305. <https://doi.org/10.1177/097325860700200302>

- Trier-Bieniek, A. (2012). Framing the telephone interview as a participant-centred tool for qualitative research: a methodological discussion. *Qualitative Research*, 12(6), 630-644.
<https://doi.org/10.1177/1468794112439005>
- Tsurkov, E., & Jukhadar, Q. (2020). *Ravaged by war, Syria's health care system is utterly unprepared for a pandemic*. Retrieved December 5 from
- UN World Population Prospects. (2019). *World Population Review*.
<https://worldpopulationreview.com/countries/iran-population/>
- UNHCR. (2020). *Lebanon Fact Sheet*. The UN Refugee Agency. Retrieved December, 29 from
- Usta, J., Farver, J. M., & Hamieh, C. S. (2015). Effects of Socialization on Gender Discrimination and Violence Against Women in Lebanon. *Violence Against Women*, 22(4), 415-431.
<https://doi.org/10.1177/1077801215603509>
- Vaismoradi, M., & Snelgrove, S. (2019). Theme in Qualitative Content Analysis and Thematic Analysis. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research; Vol 20, No 3 (2019): Qualitative Content Analysis IDO - 10.17169/fqs-20.3.3376*. <https://www.qualitative-research.net/index.php/fqs/article/view/3376/4470>
- Van Gennip, I. E., Pasman, H. R. W., Oosterveld-Vlug, M. G., Willems, D. L., & Onwuteaka-Philipsen, B. D. (2013). The development of a model of dignity in illness based on qualitative interviews with seriously ill patients. *International Journal of Nursing Studies*, 50(8), 1080-1089.
<https://doi.org/https://doi.org/10.1016/j.ijnurstu.2012.12.014>
- van Gennip, I. E., W. Pasman, H. R., Oosterveld-Vlug, M. G., Willems, D. L., & Onwuteaka-Philipsen, B. D. (2016). How Dementia Affects Personal Dignity: A Qualitative Study on the Perspective of Individuals With Mild to Moderate Dementia. *The Journals of Gerontology: Series B*, 71(3), 491-501. <https://doi.org/10.1093/geronb/gbu137>
- Van Lerberghe, W., A., M., & Kronfol, N. (2018). *The collaborative governance of Lebanon's health sector: Twenty Years of Efforts To Transform Health System Performance*.
<https://www.moph.gov.lb/>
- Van Mechelen, W., Aertgeerts, B., De Ceulaer, K., Thoonsen, B., Vermandere, M., Warmenhoven, F., Van Rijswijk, E., & De Lepeleire, J. (2012). Defining the palliative care patient: A systematic review. *Palliat Med*, 27(3), 197-208. <https://doi.org/10.1177/0269216311435268>
- Vigna, P. M., de Castro, I., & Fumis, R. R. L. (2020). Spirituality alleviates the burden on family members caring for patients receiving palliative care exclusively. *BMC Palliative Care*, 19(1), 77.
<https://doi.org/10.1186/s12904-020-00585-2>
- Vladeck, B. C., & Westphal, E. (2012). Dignity-driven decision making: a compelling strategy for improving care for people with advanced illness. *Health Aff (Millwood)*, 31(6), 1269-1276.
<https://doi.org/10.1377/hlthaff.2012.0173>
- Vrinten, C., Gallagher, A., Waller, J., & Marlow, L. A. V. (2019). Cancer stigma and cancer screening attendance: a population based survey in England. *BMC Cancer*, 19(1), 566.
<https://doi.org/10.1186/s12885-019-5787-x>
- Waldron, J. (2009). *Dignity, Rank, and Rights. The Tanner Lectures on Human Values*.
- Wang, H., Zhao, F., Wang, X., & Chen, X. (2018). To Tell or Not: The Chinese Doctors' Dilemma on Disclosure of a Cancer Diagnosis to the Patient. *Iranian Journal of Public Health*, 47(11), 1773-1774. <https://pubmed.ncbi.nlm.nih.gov/30581799>
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6294856/>
- Watch, H. R. (2019). *Lebanon: Hospital Crisis Endangering Health*. Human Rights Watch. Retrieved January, 5, 2021 from <https://www.hrw.org/news/2019/12/10/lebanon-hospital-crisis-endangering-health>

- Weaver, K., & Olson, J. K. (2006). Understanding paradigms used for nursing research. *Journal of Advanced Nursing*, 53(4), 459-469. <https://doi.org/10.1111/j.1365-2648.2006.03740.x>
- Whitehouse, J. (2020, January, 18). Human Rights. *The Value of Human Rights in Health and Social Care: from Covid-19 and beyond*. <https://www.bih.org.uk/blog/hr-health-social-care-from-covid-19-and-beyond>
- Whittemore, & Knafl. (2005). The integrative review: updated methodology. *Journal of Advanced Nursing*, 52(5), 546-553. <https://doi.org/10.1111/j.1365-2648.2005.03621.x>
- WHO. (2020). *Palliative Care*. Retrieved December, 21 from <https://www.who.int/news-room/factsheets/detail/palliative-care>
- WHO, W. H. O. (2000). *Older Population and Health System: A profile of Lebanon* https://www.who.int/ageing/projects/intra/phase_one/alc_intra1_cp_lebanon.pdf
- Woolhead, G., Calnan, M., Dieppe, P., & Tadd, W. (2004). Dignity in older age: what do older people in the United Kingdom think? *Age Ageing*, 33(2), 165-170. <https://doi.org/10.1093/ageing/afh045>
- World Atlas. (2016, September, 2016). *World Map*. Retrieved May, 3, 2020 from <https://www.worldatlas.com/webimage/countrys/me.htm>
- World Bank. (2018). *Physicians (per 1,000 people) - Lebanon*. World Health Organization's Global Health Workforce Statistics, OECD, supplemented by country data.
- License : CC BY-4.0 Retrieved December, 30 from <https://data.worldbank.org/indicator/SH.MED.PHYS.ZS?locations=LB>
- World Health Organization. (2017, June, 13, 2018). *WHO Definition of Palliative Care*. Retrieved November 9 2017 from <http://www.who.int/cancer/palliative/definition/en/>
- World Health Organization. (2021). *Quality health services and palliative care: practical approaches and resources to support policy, strategy and practice*. WHO. Retrieved December, 15 from <https://www.who.int/publications/i/item/9789240035164>
- WorldAtlas. (2021). *Maps Of Lebanon*. Retrieved December, 28 from <https://www.worldatlas.com/maps/lebanon>
- Worster, B., & Swartz, K. (2017). Telemedicine and Palliative Care: an Increasing Role in Supportive Oncology. *Current Oncology Reports*, 19(6), 37. <https://doi.org/10.1007/s11912-017-0600-y>
- Xiao, J., Ng, M. S. N., Yan, T., Chow, K. M., & Chan, C. W. H. (2021). How patients with cancer experience dignity: An integrative review. *Psycho-oncology (Chichester, England)*, 30(8), 1220-1231. <https://doi.org/10.1002/pon.5687>
- Yamout, I. R., Dakessian Sallian, S., & Beydoun, H. (2020). The State of Palliative Care During Covid-19. *Middle East journal of anesthesiology*, 27(2), 171-176.
- Yoon, S. J., Suh, S. Y., Kim, S. H., Park, J., Kim, Y. J., Kang, B., Park, Y., Kwon, J. H., Park, K., Shin, D. W., Kim, H. J., Ahn, H. Y., & Hui, D. (2018). Spiritual Well-being Among Palliative Care Patients With Different Religious Affiliations: A Multicenter Korean Study. *J Pain Symptom Manage*, 56(6), 893-901. <https://doi.org/10.1016/j.jpainsymman.2018.09.001>
- Yoshida, S., Shiozaki, M., Sanjo, M., Morita, T., Hirai, K., Tsuneto, S., & Shima, Y. (2012). Practices and evaluations of prognostic disclosure for Japanese cancer patients and their families from the family's point of view. *Palliative and Supportive Care*, 11(5), 383-388. <https://doi.org/10.1017/S1478951512000569>

Appendices

Appendix A

Syntax from CINAHL

#	Query	Limiters/Expanders	Last Run Via	Results
S16	S4 AND S9 AND S15	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	2,166
S15	S10 OR S11 OR S12 OR S13 OR S14	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	120,895
S14	TI (((cypr* OR Afghanistan* OR Bahrain* OR iran* OR iraq* OR israel* or gaza OR ghazza# OR "west bank" OR palestin* OR jordan* OR leban* OR liban OR syria* OR oman* OR qatar* OR kuwait* OR saudi* OR " Saudi arabia" or turk* OR UAE or "united arab emirates" OR egypt* OR yemen* OR Mediterranean OR muslim* OR islam* OR oriental OR arab* OR middle#east OR (((cultur* or multicultur*) N2 (divers* OR chang*))) OR AB (((cypr* OR Afghanistan* OR Bahrain* OR iran* OR iraq* OR israel* or gaza OR ghazza# OR "west bank" OR palestin* OR jordan* OR leban* OR liban OR syria* OR oman* OR qatar* OR kuwait* OR saudi*	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	120,895

	OR " Saudi arabia" or turk* OR UAE or "united arab emirates" OR egypt* OR yemen* OR Mediterranean OR muslim* OR islam* OR oriental OR arab* OR middle#east OR ((cultur* or multicultur*) N2 (divers* OR chang*))			
S13	(MM "Cultural Diversity")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	6,010
S12	(MM "Islam")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	2,237
S11	(MM "Arabs")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	1,246
S10	(MM "Middle East")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	27
S9	S5 OR S6 OR S7 OR S8	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	114,867

S8	TI (((palliat* OR terminal* OR hospice OR dying OR death) N2 (patient* OR experience* OR care OR phase OR prognosis OR ill* OR cancer)) OR " end of life" OR end-stage OR life threatening OR life limiting OR (final OR last) N2 (day*) OR " advanced cancer") OR AB (((palliat* OR terminal* OR hospice OR dying OR death) N2 (patient* OR experience* OR care OR phase OR prognosis OR ill* OR cancer)) OR " end of life" OR end-stage OR life threatening OR life limiting OR (final OR last) N2 (day*) OR " advanced cancer")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	100,213
S7	(MM "Attitude to Death")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	4,463
S6	(MM "Terminal Care") OR (MM "Terminally Ill Patients")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	18,110
S5	(MM "Palliative Care") OR (MM "Terminal Care") OR (MM "Hospice Care") OR (MM "Hospice and Palliative Nursing")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	39,822

S4	S1 OR S2 OR S3	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	114,096
S3	TI (((palliat* OR terminal* OR hospice OR dying OR death) N2 (patient* OR experience* OR care OR phase OR prognosis OR ill* OR cancer)) OR " end of life" OR end-stage OR life threatening OR life limiting OR (final OR last) N2 (day*) OR " advanced cancer") OR AB (((palliat* OR terminal* OR hospice OR dying OR death) N2 (patient* OR experience* OR care OR phase OR prognosis OR ill* OR cancer)) OR " end of life" OR end-stage OR life threatening OR life limiting OR (final OR last) N2 (day*) OR " advanced cancer")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	100,213
S2	(MM "Respect")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - CINAHL Complete	711
S1	(MM "Human Dignity") OR (MM "Self-Concept")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - CINAHL Complete	13,536

Appendix B

Appraising the evidence using the Hawker et al. (2002) tool.

Example of an appraised paper by Bagherian et al, 2019

Author and title: Bagherian et al_ Cancer patients’ perspectives
on dignity in care

Date: _____ 2019 _____

Good Fair Poor Very Poor Comment

1. Abstract and title
2. Introduction and aims
3. Method and data
4. Sampling
5. Data analysis
6. Ethics and bias
7. Findings/results
8. Transferability/generalisability
9. Implications and usefulness

Total **31**

1. Abstract and title: Did they provide a clear description of the study?	
Good ✓	Structured abstract with full information and clear title. Did not mention sample size
Fair	Abstract with most of the information.
Poor	Inadequate abstract.
Very Poor	No abstract.
2. Introduction and aims: Was there a good background and clear statement of the aims of the research?	
Good ✓	Full but concise background to discussion/study containing up-to date

	Literature review and highlighting gaps in knowledge. Clear statement of aim AND objectives including research questions. Did not have objectives
Fair	Some background and literature review. Research questions outlined.
Poor	Some background but no aim/objectives/questions OR Aims/objectives but inadequate background.
Very Poor	No mention of aims/objectives. No background or literature review.
3. Method and data: Is the method appropriate and clearly explained?	
Good	Method is appropriate and described clearly (e.g., questionnaires included). Clear details of the data collection and recording.
Fair ✓	Method appropriate, description could be better. Data described. It doesn't say where the data was collected, by whom, and how it was recorded
Poor	Questionable whether method is appropriate. Method described inadequately. Little description of data.
Very Poor	No mention of method, AND/OR Method inappropriate, AND/OR No details of data.
4. Sampling: Was the sampling strategy appropriate to address the aims?	
Good	Details (age/gender/race/context) of who was studied and how they were recruited. Why this group was targeted. The sample size was justified for the study. Response rates shown and explained.
Fair ✓	Sample size justified. Most information given, but some missing. Not much info given about the diversity of the sample
Poor	Sampling mentioned but few descriptive details.
Very Poor	No details of sample.
5. Data analysis: Was the description of the data analysis sufficiently rigorous?	
Good	Clear description of how analysis was done. Qualitative studies: Description of how themes derived/ respondent validation or triangulation. Quantitative studies: Reasons for tests selected hypothesis driven/ numbers add up/statistical significance discussed.
Fair ✓	Qualitative: Descriptive discussion of analysis. Quantitative.
Poor	Minimal details about analysis.
Very Poor	No discussion of analysis.
6. Ethics and bias: Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?	
Good	Ethics: Where necessary issues of confidentiality, sensitivity, and consent were addressed. Bias: Researcher was reflexive and/or aware of own bias.
Fair ✓	Lip service was paid to above (i.e., these issues were acknowledged).
Poor	Brief mention of issues.
Very Poor	No mention of issues.
7. Results: Is there a clear statement of the findings?	

Good ✓	Findings explicit, easy to understand, and in logical progression. Tables, if present, are explained in text. Results relate directly to aims. Sufficient data are presented to support findings.
Fair	Findings mentioned but more explanation could be given. Data presented relate directly to results.
Poor	Findings presented haphazardly, not explained, and do not progress logically from results.
Very Poor	Findings not mentioned or do not relate to aims.
8. Transferability or generalisability : Are the findings of this study transferable (generalizable) to a wider population?	
Good	Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling).
Fair ✓	Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in Question 4.
Poor	Minimal description of context/setting.
Very Poor	No description of context/setting.
9. Implications and usefulness: How important are these findings to policy and practice?	
Good ✓	Contributes something new and/or different in terms of understanding/insight or perspective. Suggests ideas for further research. Suggests implications for policy and/or practice.
Fair	Two of the above (state what is missing in comments).
Poor	Only one of the above.
Very Poor	None of the above.

Appendix C



AUB Social & Behavioral Sciences INVITATION SCRIPT

Invitation to Participate in a Research Study

This notice is for an AUB-IRB Approved Research Study

for Mrs. Silva Dakessian Sailian at AUB.

(sd61@aub.edu.lb)

I am inviting you to participate in a research study about (**EXPLORING DIGNITY IN CHRONIC AND TERMINAL ILLNESSES IN LEBANON: PATIENTS AND CAREGIVERS PERSPECTIVE** The purpose of this study is to clarify the interpretations of personal dignity in individuals facing long-term or terminal health conditions and their family caregivers. It intends to explore the experiences of dignity during interactions with health care providers and consuming health services.).

You will be asked to complete a telephone interview or an online video call to give your opinion about this topic

You are invited because we are targeting patients. You are eligible for this study if you are aged over 18, and facing a condition that needs continuous medical attention.

The estimated time to complete this interview is approximately thirty minutes

Please I will read the consent form and consider whether you want to be involved in the study.

If you have any questions about this study, you may contact the investigator/research team (Silva Dakessian Sailian, sd61@aub.edu.lb).

Appendix D

To protect research participants' and the researcher's health, the following arrangements were applied during data collection as per the recommendations of the ethics committee of the American University of Beirut.

Not recruiting anyone who has returned to Lebanon from overseas in the past 14 days to collect research data.

The researcher will be monitoring her health and seek medical opinion if she has symptoms such as cough or shortness of breath.

The researcher will be avoiding the use of buses and service taxis for traveling to research sites.

The researcher will seek medical advice if she becomes concerned about their health.

The researcher will wear masks and have hand sanitizer and tissues when visiting research sites to ensure hand hygiene.

The researcher will screen potential research participants by asking the following questions before consenting participants and collecting data.

Have you returned to Lebanon in the past 14 days (ask only if applicable)? If yes, terminate the discussion.

In the past week have you had a fever, a persistent cough, or shortness of breath? If yes, terminate the discussion and suggest the person consults a physician.

To your knowledge, have you been in contact with anyone who has been treated for a Covid-19 infection? If yes, terminate discussion and suggest the person consults a physician, gets tested for Covid-19, and self isolates for the period advised by a physician.

The researcher will be collecting data and consenting participants online/remotely whenever possible.

The researcher will observe social distancing (at least 2.0 meters between the data collector and research participant).

The researcher will collect data next to open windows and well-ventilated spaces whenever possible in face-to-face interviews.

The researcher will be using masks as well as give to participants to use during the in-person interview.

Appendix E



Participant Information Sheet Patient

Exploring Dignity in Chronic and Terminal Illnesses in Lebanon: Patients and Caregivers Perspective

My name is Silva Dakessian Sailian and I am conducting this research as a PhD student in the Palliative Care program at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to explore the interpretation and perceptions of personal dignity in Lebanese adults with chronic or terminal illnesses and how it is affected during illness and while receiving health care services.

Why have I been approached?

You have been approached because the study requires information from people who are facing long term illnesses that demand ongoing medical attention and care.

Do I have to take part?

No. It's completely up to you to decide whether you take part in this research project. You have also the right to withdraw from the interview at any time in the study.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to take part in an interview that would be either in person, or via a video call using an online platform or via regular telephone calls that would take around 30 – 60 minutes.

Will my data be Identifiable?

The information you provide is confidential. Participants will not be identifiable. The data collected for this study (audio recordings and transcripts) will be stored securely in an encrypted and password protected personal computer in the researcher's office at the American University of Beirut, and in the data storehouse (cloud-based data storage) at Lancaster University. Only the researcher conducting this study, and the research supervisors in the United Kingdom will have access to this data:

- Audio recordings will be encrypted (that is no-one other than the researcher will be able to access them) and password protected until they are destroyed by the researcher.

- Audio recordings will be destroyed immediately once they are uploaded into the researcher's personal computer that is encrypted and password protected.
- The typed version of the interview will be made anonymous by removing any identifying information including your name and stored in an encrypted and password protected personal computer of the researcher.
- If the interview takes place using an online platform, it will be videotaped or audiotaped as per your preference by the researcher.
- All your personal data will be confidential and will be kept separately from your interview responses.
- Anonymized direct quotations from your interview may be used in the reports or publications from the study, by using false names (pseudo names) so your name will not be attached to them.
- All collected data will be destroyed after ten years by the University data manager at Lancaster and by the researcher at the American University of Beirut.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to my supervisors and local authority staff members about this. If possible, I will tell you if I must do this.

What will happen to the results?

The results will be summarized and reported in a dissertation/thesis and may be submitted for publication in an academic or professional journal or presented in conferences.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher, stop the interview and seek help from medical resources.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part. Nevertheless, participants feel empowered after being able to narrate their stories and express their wishes and frustrations.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University as well as Lebanese Ethics committee at the American University of Beirut.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

- Silva Dakessian Sailian; American University of Beirut, Hariri School of Nursing- Tel: 961 350000, ext. 5967; email: sd61@aub.edu.lb
- Institutional Review Board Office, American University of Beirut, Tel: 961-1-350000 or 374374, ext. 5445. Email. irb@aub.edu.lb
- Prof Nancy Preston, Lancaster University. Faculty of Health and Medicine- Department of Health Research, Tel: +44 (0)1524 592802; n.j.preston@lancaster.ac.uk

- Dr. Yakubu Salifu, Lancaster University. Faculty of Health and Medicine-
Department of Health Research, Tel: +44 (0)1524 593722; y.salifu@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

- a) Institutional Review Board Office, American University of Beirut, Tel: 961-1-350000 or 374374, ext. 5445. Email. irb@aub.edu.lb
- b) Katharina Janke; Director of Studies, Palliative Care. Tel: +44 (0)1524 595103. Email: k.jankemarie@lancaster.ac.uk. Faculty of Health and Medicine; Department of Health Research; Lancaster University , LA1 4YG, United Kingdom

Thank you for taking the time to read this information sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, you will be referred to contact your primary physician or to an accessible free community services where psychological support is provided, such as

- 1) Idrrac 961- 76- 100576
- 2) Blue mission organization 961- 07-732636 or 961- 78-965062
- 3) Embrace 1564.

Appendix F



Participant Information Sheet Caregiver

Exploring Dignity in Chronic and Terminal Illnesses in Lebanon: Patients and Caregivers Perspective

My name is Silva Dakessian Sailian and I am conducting this research as a PhD student in the Palliative Care program at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to explore the interpretation and perceptions of personal dignity in Lebanese adults with chronic or terminal illnesses and how it is affected during illness and while receiving health care services.

Why have I been approached?

You have been approached because the study requires information from caregivers' of people who are facing long term illnesses that demand ongoing medical attention and care.

Do I have to take part?

No. It is completely up to you to decide whether you take part in this research project. You have also the right to withdraw from the interview at any time in the study.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to take part in an interview that would be either in person, or via a video call using an online platform or via regular telephone calls that would take around 30 – 60 minutes.

Will my data be Identifiable?

The information you provide is confidential. Participants will not be identifiable. The data collected for this study (audio recordings and transcripts) will be stored securely in an encrypted and password protected personal computer in the researcher's office at the American University of Beirut, and in the data storehouse (cloud-based data storage) at Lancaster University. Only the researcher conducting this study, and the research supervisors in the United Kingdom will have access to this data:

- Audio recordings will be encrypted (that is no-one other than the researcher will be able to access them) and password protected until they are destroyed by the researcher.

- Audio recordings will be destroyed immediately once they are uploaded into the researcher's personal computer that is encrypted and password protected.
- The typed version of the interview will be made anonymous by removing any identifying information including your name and stored in an encrypted and password protected personal computer of the researcher.
- If the interview takes place using an online platform, it will be videotaped or audiotaped as per your preference by the researcher.
- All your personal data will be confidential and will be kept separately from your interview responses.
- Anonymized direct quotations from your interview may be used in the reports or publications from the study, by using false names (pseudo names) so your name will not be attached to them.
- All collected data will be destroyed after ten years by the University data manager at Lancaster and by the researcher at the American University of Beirut.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to my supervisors and local authority staff members about this. If possible, I will tell you if I must do this.

What will happen to the results?

The results will be summarized and reported in a dissertation/thesis and may be submitted for publication in an academic or professional journal or presented in conferences.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher, stop the interview, and seek help from medical resources.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part. Nevertheless, participants feel empowered after being able to narrate their stories and express their wishes and/ or frustrations.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University as well as Lebanese Ethics committee at the American University of Beirut.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

- Silva Dakessian Sailian; American University of Beirut, Hariri School of Nursing- Tel: 961 350000, ext. 5967; email: sd61@aub.edu.lb
- Institutional Review Board Office, American University of Beirut, Tel: 961-1-350000 or 374374, ext. 5445. Email. irb@aub.edu.lb
- Prof Nancy Preston, Lancaster University. Faculty of Health and Medicine- Department of Health Research, Tel: +44 (0)1524 592802; n.j.preston@lancaster.ac.uk

○ Dr. Yakubu Salifu, Lancaster University. Faculty of Health and Medicine-
Department of Health Research, Tel: +44 (0)1524 593722; y.salifu@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

- a) Institutional Review Board Office, American University of Beirut, Tel: 961-1-350000 or 374374, ext. 5445. Email. irb@aub.edu.lb
- b) Katharina Janke; Director of Studies, Palliative Care Tel: +44 (0)1524 595103 Email: k.jankemarie@lancaster.ac.uk Faculty of Health and Medicine, Department of Health Research Lancaster University , LA1 4YG, United Kingdom

Thank you for taking the time to read this information sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, you will be referred to contact your primary physician or to an accessible free community services where psychological support is provided, such as

- 1) Idrrac 961- 76- 100576
- 2) Blue mission organization 961- 07-732636 or 961- 78-965062
- 3) Embrace 1564.

Appendix G



Informed Consent Form Patient

Exploring Dignity in Chronic and Terminal Illnesses in Lebanon: Patients and Caregivers Perspective

We are asking if you would like to take part in a collaborative research project between the American University of Beirut and Lancaster University, U.K., that explores personal dignity in patients and their caregivers with long term illnesses.

Before you consent to participate in the study, we ask that you read the participant information sheet. If you have any questions or queries before giving consent please speak to the principal investigator, Silva Dakessian Sailian at sd61@aub.edu.lb ; or +961 01350000, ext. 5967.

Please read each statement:

I have received and understood the Study Information about the project: “Exploring Dignity in Advanced Chronic and Terminal Illnesses in Lebanon: Patients and Caregivers Perspective”

I understand that I have been approached because my physician finds me suitable to participate in this study

I understand that the project entails interviews that could be in person, or through online video call (using a social medium) or via telephone that may last for around thirty – sixty minutes

I understand that my participation is voluntary and whether I decide to take part will have no effect on my relationship with my health care service or physician.

I understand that I am free to withdraw from the project at any time or refuse to answer a question, without giving justification, and this will not affect my medical care or legal rights.

I understand that my interview will be audio recorded or video recorded (if I choose online platform) and then made into an anonymised written transcript stored securely at Lancaster University, UK and at the American University of Beirut.

I understand that the interview will be video-taped or or audiotaped as per my preference if it takes place using an online video call medium.

I understand that if I feel anxious during the interview, I can stop the interview, and take a break. If I feel very upset the researcher will refer me to my primary physician or provide information on community free services for psychological support.

Most likely the participants will be interviewed from home either in person, or through telephone or online audio-video platform suitable for the participant.

I will try not to say names of institutions or health care staff members in the interview, and if I do the researcher will anonymize it and not include it in the research report.

I understand that the information from my interview will be pooled with other participants' responses, anonymized and may be published.

I understand some anonymised quotes from the study may be used in reports and academic papers but these will not be shared in other ways.

I understand that once my data have been anonymized and incorporated into themes it might not be possible for it to be withdrawn after two weeks of data collection, though every attempt will be made to extract my data.

I understand that the researcher will discuss data with their supervisor as needed.

I understand any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the researchers may need to share this information with local authorities and *supervisors* from Lancaster University.

I understand that the interview records will be monitored and may be audited by the American University Institutional Review board during the research, maintaining confidentiality.

I understand that taking part in face to face or telephone or online interviews may have an indirect benefit on my psychological state by allowing me personal space to voice my concerns, express wishes, frustrations and reflect on past experiences.

I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished.

I have been able to ask questions about the study, and these were answered in a way that I understand and am happy with.

I understand that I can express my complaints or obtain further information about the study through contacting

- Institutional Review Board Office, American University of Beirut, Tel: 961-1-350000 or 374374, ext. 5445. Email. irb@aub.edu.lb
 - Prof Nancy Preston, Lancaster University. Faculty of Health and Medicine- Department of Health Research, Tel: +44 (0)1524 592802; n.j.preston@lancaster.ac.uk
 - Dr. Yakubu Salifu, Lancaster University. Faculty of Health and Medicine- Department of Health Research, Tel: +44 (0)1524 593722; y.salifu@lancaster.ac.uk
-

I agree to take part in the above study. _____

For low literacy or visually impaired participants a witness, independent of the research team, will be present to validate the form.

Name of Participant _____

Signature _____

Date _____

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Signature of Researcher /person taking the consent _____

Date _____ Day/month/year

One copy of this form will be given to the participant and the original kept in the files of the researcher at American University of Beirut.

Appendix H



Informed Consent Form Caregiver

Exploring Dignity in Chronic and Terminal Illnesses in Lebanon: Patients and Caregivers Perspective

We are asking if you would like to take part in a collaborative research project between the American University of Beirut and Lancaster University, U.K., that explores personal dignity in patients and their caregivers with long term illnesses.

Before you consent to participate in the study, we ask that you read the participant information sheet. If you have any questions or queries before signing the consent form please speak to the principal investigator, Silva Dakessian Sailian via emailing sd61@aub.edu.lb or phone +961 01 350000 ext. 5967.

Please read each statement:

I have received and understood the Study Information about the project: “Exploring Dignity in Chronic and Terminal Illnesses in Lebanon: Patients and Caregivers Perspective”

I understand that I have been approached because the physician of my family member finds me suitable to participate in this study

I understand that the project entails either in person interviews, or video calls or using a regular telephone that may last for thirty-sixty minutes.

I understand that my participation is voluntary and whether I decide to take part will have no effect on my relationship or the relationship of my relative with the health care service or physician.

I understand that I am free to withdraw from the project at any time, or refuse to answer a question without any justification, and this will not affect my or my relative’s medical care or legal rights.

I understand that my interview will be audio recorded or video recorded (if choose online platform) and then made into an anonymized written transcript stored securely at Lancaster University, UK and at the American University of Beirut.

I understand that the interview will be video-taped or audiotaped as per my preference if it takes place using an online video call medium.

I understand that if I feel anxious during the interview, I can stop the interview, and take a break. If I feel very upset, the researcher will be providing me information about community free service for psychological support.

Most likely the interview will be carried while the caregiver is at home or workplace using a convenient online audio-video platform or regular telephone.

I will try not to say names of institutions or health care staff members in the interview, and if I do the researcher will anonymize it and not include it in the research report.

I understand that the information from my interview will be pooled with other participants' responses, anonymized and may be published.

I understand some anonymised quotes from the study may be used in reports and academic papers, but these will not be shared in other ways.

I understand that once my data have been anonymized and incorporated into themes it might not be possible for it to be withdrawn after two weeks of data collection, though every attempt will be made to extract my data.

I understand that the researcher will discuss data with their supervisor as needed.

I understand any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the researchers may need to share this information with local authorities and *supervisors* from Lancaster University.

I understand that the interview records will be monitored and may be audited by the American University Institutional Review board during the research, maintaining confidentiality.

I understand that taking part in online or telephone interviews may have an indirect benefit on my psychological state by allowing me personal space to voice my concerns, express wishes, frustrations and reflect on past experiences.

I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished.

I have been able to ask questions about the study, and these were answered in a way that I understand and am happy with.

I understand that I can express my complaints or obtain further information about the study through contacting

- Institutional Review Board Office, American University of Beirut, Tel: 961-1-350000 or 374374, ext. 5445. Email. irb@aub.edu.lb
- Prof Nancy Preston, Lancaster University. Faculty of Health and Medicine- Department of Health Research, Tel: +44 (0)1524 592802; n.j.preston@lancaster.ac.uk
- Dr. Yakubu Salifu, Lancaster University. Faculty of Health and Medicine- Department of Health Research, Tel: +44 (0)1524 593722; y.salifu@lancaster.ac.uk

For low literacy or visually impaired participants a witness, independent of the research team, will be present to validate the form.

I agree to take part in the above study.

Name of Participant _____

Signature _____

Date _____

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Signature of Researcher /person taking the consent _____

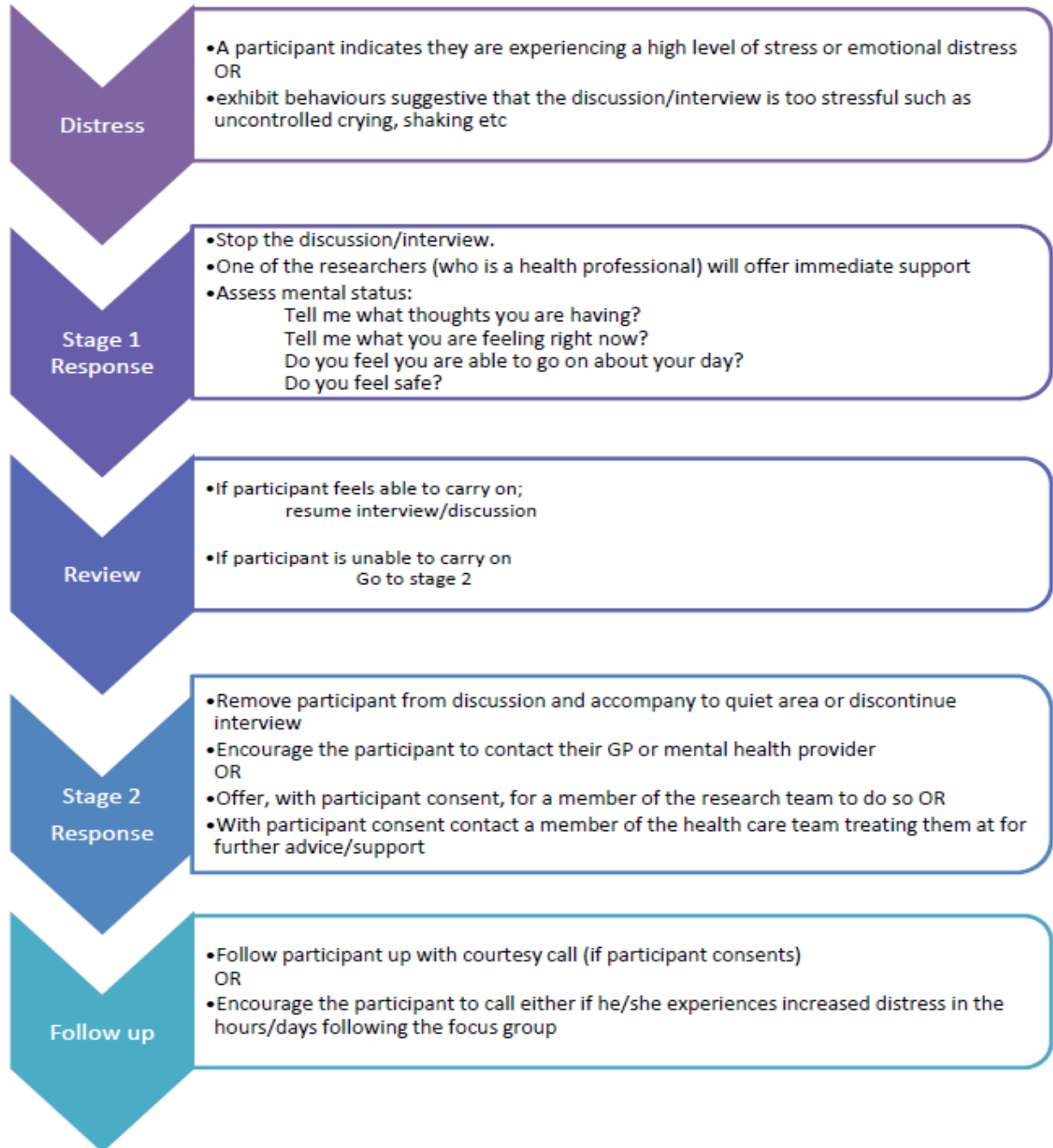
Date _____ Day/month/year

One copy of this form will be given to the participant and the original kept in the files of the researcher at American University of Beirut.

Appendix I

Distress Protocol

Distress Protocol 1: The protocol for managing distress in the context of a research focus group /interview
(Modified from : Draucker C B, Martsof D S and Poole C (2009) Developing Distress Protocols for research on Sensitive Topics.
Archives of Psychiatric Nursing 23 (5) pp 343-350)



Appendix J



Topic Guide for Patients

Interview stage	Questions
Introduction	My name is Silva Dakessian Sailian and I am conducting research project as part of my PhD dissertation. My research topic is about dignity in patients and family members with illness.
Consent to interviewing	
Consent to recording	
Background and contextual	<p>Tell me about yourself, your age, work, family role... Would you mind me asking about</p> <ol style="list-style-type: none"> 1. Your illness 2. When did you start feeling ill, how did you know, time of diagnosis... 3. How long have you been visiting your doctor; how many times have you been in the hospital in the past year
<p>Definitional questions</p> <p>The researcher will use the term used by the patient to further explore the topic</p>	<p>Dignity is often mentioned to be important in health care and for patients</p> <ol style="list-style-type: none"> 1. What does the term or the concept of dignity mean to you? What other terms or words would you use to describe it? 2. How would you define personal dignity or understand it. 3. Is it associated with particular places or people or stages in your life? Does it bring to mind images . . . or other words? 4. Can you tell me about what are the qualities of having or preserving personal dignity? Or what meaning does it hold to you? <p>I'd like to move on to your experience of dignity in your illness . . . and encounter with health care provides</p>

<p>Core Discussion using prompt and follow-up questions</p>	<ol style="list-style-type: none"> 1. How did the phenomenon of dignity change if any, with your (or family member's) illness experience? If so how, what was it related to? 2. Can you think of a particular time when you experienced loss or almost loss of dignity in (or family member's) illness experience (diagnosis, progression....)? How did you feel? 3. What about your encounters with the health care providers (in or outside hospital setting) did if effect your dignity or that of your family member? Did hospital admission or hospital context effect it? If yes, how? 4. Whether there were any particular situations while in the hospital ward when you felt you lost, or could have lost, your "dignity" or word used by patient or family member. If yes, explore: 5. What actions or experiences can you recall with nurses, physicians that challenged your dignity, or made you feel uncomfortable? 6. What actions or experiences can you recall with nurses, physicians or other health providers that made you feel dignified? 7. How did hospital staff affect the situation (did they make the situation better or worse), anything else that you would have liked staff to do in this situation. 8. How did losing dignity or conserving it affect your wellbeing? How? 9. Some studies say that dignity is related to the physical symptoms, presence of social support and personal characteristics of the individual, do you agree? To what aspect, please elaborate
<p>Closing the interview</p>	<ol style="list-style-type: none"> 1. What actions or advice would you recommend to health care providers, friends or family members that could conserve the dignity of an ill person? 2. How do you think the occurrence of Covid-19 pandemic affected your perceptions on dignity and how it changed your interactions with health care services? 3. Is there anything else that I didn't ask and you want to inform me? Any burning issue that you would like to share with me? 4. Thank the participant and ensure he/she is in good place and comfortable

Appendix K



Topic Guide for Caregivers

Interview stage	Questions
Introduction	My name is Silva Dakessian Sailian and I am conducting research project as part of my PhD dissertation. My research topic is about the understanding the meaning of dignity in patients with illness and their family members as well as factors influencing it.
Consent to interviewing	
Consent to recording	
Background and contextual	<p>Tell me about yourself, your age, work, family role... Would you mind me asking about</p> <ol style="list-style-type: none"> 4. How long have you been taking care of your relative, to what extent? 5. How was your experience of caregiving till now?
<p>Definitional questions</p> <p>The researcher will use the term used by the patient to further explore the topic</p>	<p>Dignity is often mentioned to be important element in quality health care for patients with advanced chronic or terminal illnesses</p> <ol style="list-style-type: none"> 5. What does the term or the concept of dignity mean to you? What other terms or words would you use to describe it? 6. How would you define personal dignity or understand it? 7. Is it associated with places or people or stages in your life? Does it recollect images . . . or other words? 8. Can you tell me about what are the qualities of having or preserving personal dignity? Or what meaning does it hold to you? <p>I'd like to move on to your experience of relative's dignity in illness . . . and the encounter with health care provides</p>

<p>Core Discussion using prompt and follow-up questions</p>	<ol style="list-style-type: none"> 10. How did the phenomenon of dignity change if any, with your family member’s illness experience? If so how did it change, what was it related to? 11. Can you think of a time when your family member experienced loss or almost loss of dignity in his/ her illness experience (diagnosis, progression....)? How did you feel? 12. What about the encounters with the health care providers (in or outside hospital setting- with nurses, physicians etc.) did the interaction affect the dignity of your family member? Did hospital admission or hospital context affect it? If yes, how? 13. Whether there were any situations while in the hospital ward when your family member lost, or could have lost, the sense of “dignity” or word used by family member. If yes, explore: 14. What actions or experiences can you recall with nurses, physicians that challenged the dignity of your patient, or made him feel uncomfortable? 15. What actions or experiences can you recall with nurses, physicians or other health providers that made your family member feel dignified? 16. How did hospital staff affect the situation (did they make the situation better or worse), anything else that you would have liked staff to do in this situation. 17. How did losing the dignity of your sick family member or conserving it affect his/her wellbeing? 18. Some studies say that dignity is related to the physical symptoms, presence of social support and personal characteristics of the individual, do you agree? To what aspect, please elaborate 19. How do you think an individual’s gender, marital status, education, employment, financial status, affect dignity, in what capacity?
<p>Closing the interview</p>	<ol style="list-style-type: none"> 5. What actions or advice would you recommend to health care providers, friends or family members that could conserve the dignity of an ill person? How do you preserve the dignity of your relative? 6. Is there anything else that I didn’t ask, and you want to inform me about? Any burning issue that you would like to share with me? 7. Thank the participant and ensure he/she is comfortable and well,

Appendix L Coding on Nvivo

were here. If they don't respect or care for me and I don't respect them, do you think they would have come to see me? No, of course not.

Interviewer: did their presence and visit made you feel supported, or more comfortable?

Interviewee: Of course, every time somebody visits you, I get refreshed more, like the flower that is drying up

Interviewer: what are the things that make you feel happy or proving your existence and identity in the society and the family? Your role is preserved

Interviewee: My family, my family. They asked a scholar, who do you want to be better than you? Who do you want to be better than you? Your wife, our brother, your father ...etc. . He said, what are you talking about, I only want my son to be better than me, and this is a scholar, thinker... I only prefer my son to be better than me. Therefore, my family is the basis, they refresh me and give me life and they are the ones who destroy me. My wife treats me like a baby boy. Now like a child. She tells me ask me anything you want or desire, she tells me if you please come and take your medicine. This treatment comforts me, it helps my psychology, provides me comfort. I feel that there is a person in support of me, standing with me; there is a person who is protecting part of me

Interviewer: is it the kind speech that helps?

Interviewee: of course of course. We go out for family trips to Wazzani (border to Israel), we go to the river there, I relax there, I forget my worries and my tiredness. Just like the worker who works all day, goes there, you wash, you eat and drink and you feel relaxed. I am like this.

Interviewer: Once you are outside for a pleasure trip, you relax

Interviewee: yes I am comforted like this, my self-calms down. Unless, God forbid, I have the pain

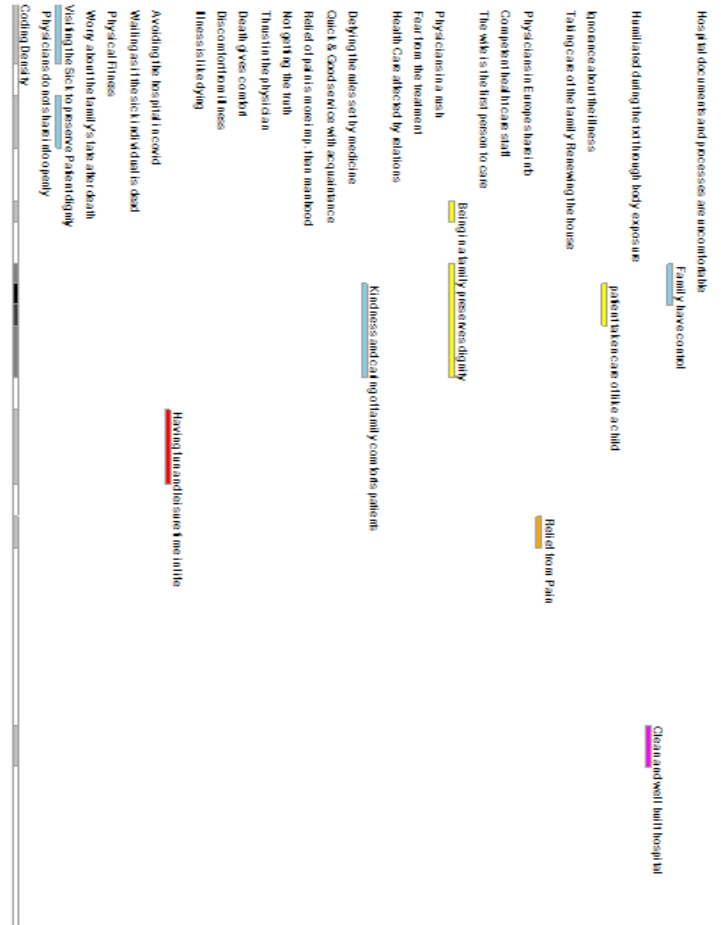
Interviewer: if you have the pain, you remember your condition. ----- Mr. Seif when was the last time you were admitted to the hospital? Why am I asking this to you. I want you to go back and remember the last time, a day, you were in a hospital setting or in the clinic Tell me how was the treatment of the medical staff with you? In what way did the staff treat you, and how this treatment affect your psychology, your self esteem?

Interviewee: I was hospitalized in the governmental hospital of Beirut, Now , in the follow ups, I used to go to see the physician in the clinic, at the kornish (o outside hospital setting), the name is shehabi... Beirut el hukumi, is poor , the hospital ... hmmm , the live come out dead from there. The living goes there and comes out dead. Crowds , the Syrians, Palestinians, are all there. the hospital is poor, unclean, the care is minimal, and ... you are talking about the Beirut governmental hospital. You are not talking about a teaching hospital in the ashrafies what's its name ?

Interviewer: Hotel Dieu

Interviewee: yes Hotel Dieu or Jesus heart hospital..

Interviewer: It's a different thing, different environment



Appendix M

A 15-Point Checklist of Criteria for Good Thematic Analysis Process (Braun and Clarke, 2006)

Transcription	1.	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'.
Coding	2.	Each data item has been given equal attention in the coding process.
	3.	Themes have not been generated from a few vivid examples (an anecdotal approach) but, instead, the coding process has been thorough, inclusive and comprehensive.
	4.	All relevant extracts for all each theme have been collated.
	5.	Themes have been checked against each other and back to the original data set.
	6.	Themes are internally coherent, consistent, and distinctive.
Analysis	7.	Data have been analysed rather than just paraphrased or described.
	8.	Analysis and data match each other – the extracts illustrate the analytic claims.
	9.	Analysis tells a convincing and well-organised story about the data and topic.
	10.	A good balance between analytic narrative and illustrative extracts is provided.
Overall	11.	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.
Written report	12.	The assumptions about ThA are clearly explicated.
	13.	There is a good fit between what you claim you do, and what you show you have done – ie, described method and reported analysis are consistent.
	14.	The language and concepts used in the report are consistent with the epistemological position of the analysis.
	15.	The researcher is positioned as <i>active</i> in the research process; themes do not just 'emerge'.