



**DYING AT HOME:
RETRIEVING A HOSPICE PALLIATIVE CARE
PRACTICE THROUGH CARE ETHICS**

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Dissertation presented in partial fulfilment of the requirements for the Degree of
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Abstract

This work will discuss dying at home as a practice which is being replaced by dying in a clinical setting thus giving rise to several end of life bioethical dilemmas. The combination of shifting death to the hospital and medical advances, paved the way to new bioethical issues pertaining to end of life care. A paradoxical situation in which on one hand life was being prolonged and on the other hand hastened, started to emerge. The emergence of hospice palliative care was a result of the dissatisfaction with how dying men and women were being cared for, and an attempt to offer an alternative, dignified care to the dying. The philosophy of hospice palliative care is considered to share common features with care ethics, and thus, a care ethics framework is deemed to be the most suitable in solving hospice palliative care ethical dilemmas. Considering caring for the dying from a care ethics approach gives a new meaning to the dying process as it is through care that humans connect, value each other, and respond to each other's needs, values which are synonymous with hospice palliative care. The ever-changing demographics wherein people suffering from a life-limiting disease are living longer, will result in an increased demand for hospice palliative care. This requires more support in terms of research, legislation, funding, awareness, and equitable access. The reinforcement and promotion of hospice palliative care as a form of care ethics might be the answer that counteracts end of life bioethical issues, only if society would learn to place more emphasis on caring rather than curing.

Keywords: death and dying, medicalisation, care ethics, hospice palliative care, home care.

Dedication

*To the Hospice patients and their families
with whom I had the honour and privilege to cross paths.
Their resilience, strength, love, and experiences
are my inspiration.*

*Frequently I am asked
'But what do you do at hospice?'
Frequently I find myself stuck on how I am going to explain this well
Mostly because
It is a vocation beyond words
How do you verbalise your deepest moments?
How do you verbalise the importance that a kind look or gentle touch can have on a
human being that is suffering?
I can go into the practicalities of what we do day in day out
But that does not define hospice care
For it is so much more
Beyond all words*

*It is a gentle hand on one's shoulder
Reassuring that someone is there*

*It is a gentle hand guiding
Encouraging patients and families through the hurdles they face daily*

*It is a hand that keeps one steady
When the world seems to be falling apart and everyone feels like faltering*

*It is a look of the most gentle of kindness that while the world looks away as these
moments feel like a failure, it looks on and knowing this is no failure, it acknowledges
this as a natural path that all need to go through*

*It is that voice that whilst the rest of the world is trying to ignore what is happening or
mellow it down, this one acknowledges what is happening and reassures that it is okay
to feel exhausted and need help*

*It is a love that sees all
Ignores none
And makes sure that while the world is drifting away
It remains there.*

Roseanne Camilleri, SN
Hospice Malta
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Introduction

i. Background

“In this world, nothing is certain except death and taxes.”¹ Whilst the latter is at times questionable, the former is by all means true. Even though death’s certainty is unequivocal, humans have been preoccupied with it since time immemorial. Over time, the level of preoccupation changed, ostensibly becoming worse as years turned into centuries. It seemed that the more the world developed, the more the wisdom related to dying matters was being lost. With the emergence of medical technology, death, once considered a natural event and which mostly happened at one’s own home and in the community, was gradually shifted to the hospital setting and transformed into a medical event. Technology seemed to be propagating the illusion that death could be avoided or even defeated. This stance may be somewhat understandable since we are “wired to survive.”² However, the way in which people were being kept alive in hospitals when it was clear that their time has come to an end, questioned the care they were receiving.

Medical technology was not the sole factor which contributed to the shift of dying to the hospital. Society was becoming more secular and the family structure changed, making caring for a dying person at home more challenging. This situation was further compounded by the fact that death was being viewed as a taboo subject which “doctors failed to mention, families failed to witness, and the hospital promised to conquer,”³

¹ National Constitution Centre, “Benjamin Franklin’s Last Great Quote and the Constitution,” accessed February 14, 2022, <https://constitutioncenter.org/blog/benjamin-franklins-last-great-quote-and-the-constitution>.

² L.S. Dugdale, *The Lost Art of Dying. Reviving Forgotten Wisdom* (New York: HarperCollins Publishers, 2020), 14.

³ *Ibid.*, 84.

and which thus led to a notion of a death-denying society. Paradoxically, a movement which promoted the termination of life on one's own terms; mainly euthanasia and physician assisted suicide, was gaining grounds.

The beginning of the study of bioethics and the birth of the modern Hospice Movement, attempted to rectify this situation. It is argued that palliative care "answered to some extent the calls for euthanasia."⁴ Hospice advocated a total pain approach to care by which the physical, emotional, spiritual, and social situation of a dying person were taken into consideration. It also sought to return the dying process to the home or at least the community setting.

My role as a qualified nurse for the past twenty eight years, has brought me face to face with someone's dying process mostly in a hospital setting. For the past four and a half years, I have been practising as a community nurse within Hospice Malta so my experience of the dying process of 'my' patients has changed considerably since a number of patients die at their home.

The inspiration behind this work is a result of one such experience in which the patient died at home, even though initially the family had stated that they preferred that this happens in the hospital. The feedback I received from the family after the patient died was that they were grateful that the patient had been cared for and died at home, that they were able to accompany their loved one till the very end, and that the two teenage children were able to say their final goodbyes to their dying parent. Amidst all the sorrow, it was a positive experience. Admittedly, this was possible because of

⁴ Keri Thomas, *Caring for the Dying at Home. Companions on the Journey* (Oxford: Radcliffe Medical Press, 2003), 20.

several crucial factors. The support system of the family was strong, their general practitioner was involved and available when and as required, and a referral to Hospice was done around four months before the patient died, a sufficient enough time to foster a trusting, caring relationship between the patient, family, and the hospice team. The patient was kept as comfortable as possible, symptoms were well controlled, and no extreme measures of care were employed.

ii. Dissertation Statement

Framing hospice palliative care as a form of care ethics, I argue that returning the process of dying from the clinical setting back to the home is likely to resolve many bioethical dilemmas typically associated with the end of life.

iii. Terminology

Hospice care, palliative care, and hospice palliative care are nuanced and are many a time confused and used interchangeably. Since hospice care aims towards the provision of symptom control and a good quality of life at the end of life, it equates to palliative care. Thus, for ease of reading and in order to avoid confusion, the term *hospice palliative care* will be used throughout the whole text.

iv. Methodology

This dissertation will be presented in the form of a bibliographic research in which a considerable amount of journal articles, books, and guidelines, amongst other data sources, were appraised. An ethics of care framework will be considered as it shares common values with hospice palliative care. The application of care ethics in hospice palliative care can lead to address otherwise complicated end of life bioethical

dilemmas. Where applicable, reference to statistical data pertinent to the dissertation, kindly provided by Hospice Malta, will also be made.

v. Structure

This dissertation will be divided into three chapters. In Chapter 1, a number of important factors considered responsible for the shifting of dying at home to dying in a hospital setting, will be discussed. This chapter will be divided into three sections in which medicalisation of death, socio-economic factors, and finally, the links these factors might have with the wish to postpone or to hasten death, will be explored.

Chapter 2 will be dedicated to care ethics and will evaluate three out of the five major attributes of care ethics as described by Virginia Held.⁵ It will be divided into three sections. In the first section, the moral prominence of responding and attending to the needs of others, will be discussed. The value of emotions will be explored in section two, whilst section three will be dedicated to care as a personal and public value.

Chapter 3 will argue for the need of a cultural change as a possible means of responding to the issues discussed in chapter 1, and also as a reaffirmation of hospice palliative care as a form of care ethics as was discussed in chapter 2. This chapter will be divided into three sections. Section one will discuss the need to broaden the understanding of hospice palliative care both on a local and global level. The second section will explore the course of action needed to increase the public dimension of hospice palliative care, including financial considerations. Lastly, section three will be devoted to the understanding of the art of dying well and the relevance it holds in today's contemporary society.

⁵ Virginia Held, *The Ethics of Care: Personal, Political, and Global* (New York: Oxford University Press, 2006), 9-13.

Chapter One: The Shift of Dying in a Hospital Setting: Some Causes and Implications

The events surrounding death and dying have noticeably changed in the past six decades or so. Described by the medievalist Philippe Ariès as “an important physical phenomenon: the displacement of the site of death,”¹ the shift of dying from home to the hospital setting is presumably the most notable and debated of these events in view of the myriad of personal, psychological, social, cultural, and bioethical concerns and implications.

This shift started to take place mostly after World War II as a result of advances in science, organ transplantation, research, pharmacological developments, and novel medical technology. Changes in societal make-up which include family dynamics, housing, and accessibility to healthcare also played a major part for this shift to happen. Societies became more secular, families were getting smaller, and conversely, caring for a dying person at home was becoming humanely and logistically more challenging. Also, technology and medicalisation raised the hope that life could be extended interminably, and perhaps death defeated once and for all.

All these changes came at a cost, albeit not of an exclusively monetary one. Ethics is now treading in uncharted territory, since this shift harboured new dilemmas of moral and ethical concerns. Allen Verhey, professor of theological ethics, aptly described the shift of dying from home to hospital and its consequences in the following manner:

When dying was moved to the hospital...there were some profound, if unintended, consequences for the dying role. Most notably, it was simply undercut, replaced by the “sick role.” ...The dying were no longer treated as if they were dying: they were treated like

¹ Philippe Ariès, *Western Attitudes Towards Death from the Middle Ages to the Present* (Baltimore, MD: Johns Hopkins University Press, 1974), 87.

anyone else who was recovering from major surgery or a serious disease. You do not go to hospital, after all, to die. You go there to get better... . So, suddenly, no one was “dying” anymore. They were just “sick.” That spelled the end of the “dying role” with its rituals and community. All that was left was “the sick role, and of course, death itself.”²

This chapter is divided into three sections. The first section will focus on medical technology and the medical imperative and how, as a result, death has become medicalised. Socio-economic factors will be discussed in section two by taking into consideration the society’s portrayal of death, family dynamics, and health-related expenditure. The third section will attempt to draw links between the medicalisation of death and the socio-economic factors described and how these lead to therapeutic obstinacy as means of postponing death on the one hand, and the wish to hasten death on the other.

1.1 Medicalisation of Death

As a term, medicalisation “has become synonymous with the sense of a profession reaching too far: into the body, the mind, and even the soul itself.”³ Medicalisation is understood “as a process by which non-medical issues become defined and treated as medical problems, usually in terms of illness or disorders.”⁴ However, even though medicalisation as a subject has been interminably discussed and written about, there still remains an ambiguity in the articulation of its definition,⁵ since it can be used in such a broad a manner as to “defeat understanding.”⁶

² Allen Verhey, *The Christian Art of Dying: Learning from Jesus*, 2011, quoted in M. Therese Lysaught, “Ritual and Practice,” in *Dying in the Twenty-First Century Toward a New Ethical Framework for the Art of Dying Well*, ed. Lydia S. Dugdale (Massachusetts: The MIT Press, 2017), 73.

³ David Clark, “Between Hope and Acceptance: the Medicalization of Dying,” *British Medical Journal* 324 (2002): 905.

⁴ Peter Conrad, “Medicalization and Social Control,” *Annual Review of Sociology* 18 (1992): 209.

⁵ *Ibid.*, 210.

⁶ Eric J. Cassell, “The Sorcerer’s Broom: Medicine’s Rampant Technology,” *The Hastings Center Report* 23, no.6 (1993): 32.

It is well documented that like birth, over the years death has become intrinsically medicalised. Both processes at the opposite spectrum of life used to take place mainly at one's home, with family members and to a certain extent the community, being active participants throughout. Death was considered, understood, and accepted as a natural process; the final stage of one's life. It was an accepted fact that old people die, people afflicted by terminal disease die, and that children might succumb to yet incurable childhood diseases. Medicalisation changed this overtly natural view; the acceptance of life and death.

As medicalisation became more diffused and hence accepted as the new norm, society started to postulate "that every cause of death can be resisted, postponed, or avoided."⁷ Seminal works by Ivan Illich,⁸ Philippe Ariès,⁹ Elizabeth Kübler Ross,¹⁰ and Dame Cicely Saunders¹¹ amongst others, critiqued and questioned various aspects of this state of affairs. The 'why' of death as a natural process was being taken over by technology, while the 'how' of what once was considered a 'tamed' death was being transformed into a 'forbidden' one. Also, the 'how' and 'why' as a consequence of these new realities dying persons were receiving a less than desirable end of life care.

1.1.1 Medical Technology

Medical technology is not intrinsically negative since when applied judiciously, it is a means of facilitating the restoration of health and improving the quality of life of those

⁷ Zygmunt Bauman, *Mortality, Immortality and Other Life Strategies*, 1992, quoted in Clark, "Between Hope and Acceptance," 905.

⁸ See, Ivan Illich, "Medical Nemesis," *Journal of Epidemiology & Community Health* 57, no.12 (2003): 919-922, <http://dx.doi.org/10.1136/jech.57.12.919>.

⁹ See, Ariès, *Western Attitudes Towards Death*.

¹⁰ See, Elizabeth Kübler Ross, *On Death and Dying: What the Dying Have to Teach Doctors, Nurses, Clergy & Their Own Families* (New York: Scribner Book Company, 2014).

¹¹ See, Cicely Saunders, *Watch with Me: Inspiration for a Life in Hospice Care* (Lancaster: Mortal Press, 2003).

who require and would benefit from it. However, its indiscriminate use without due consideration to the possible negative physical, psychological, and social effects that this may leave on a person, is a cause of concern and endless bioethical debates. It is argued that since medical technology took over, it is becoming increasingly difficult to discern when a person is actively dying. Sadly, as a consequence, “the line between living and dying has become steadily more obscure.”¹²

Medicalised dying can also be interpreted as the care, such as symptom control, a person receives during the actual dying process, which is good in itself. However, the “critique concerns the forms of medicalized dying - aggressive extension or premature termination of life - that both exemplify and perpetuate the belief that dying is a medical crisis from which patients must be rescued.”¹³ Dying is rendered a technicality in which technology is utilised to rescue the body “from the threat to its functioning and integrity.”¹⁴ Dying is a dual process; the death of the body and the death of the person which are differentiated since the former is measurable, whilst the latter is not.¹⁵ French philosopher Michel Foucault described the separation of the human body from the identity of a person, a way in which physicians tend to look at their patients, as a “dehumanising aspect of medicine” for which he coined the term ‘medical gaze.’¹⁶ It can be argued that the ‘medical gaze’ can be more apparent in a hospital rather than in the

¹² Daniel Callahan, “Death, Mourning, and Medical Progress,” *Perspectives in Biology and Medicine* 52, no. 1 (2009): 107.

¹³ Peter T. Hetzler III and Lydia S. Dugdale, “How Do Medicalization and Rescue Fantasy Prevent Healthy Dying?” *AMA Journal of Ethics* 20, no.8 (2018): E767.

¹⁴ Eric J. Cassell, “Dying in a Technological Society,” *Hastings Center Studies* 2, no.2 (May 1974): 31

¹⁵ *Ibid.*, 33.

¹⁶ Rhona Winnington, Eleanor Holroyd, and Shelaine Zambas, “The Socio-Political Debate of Dying Today in the United Kingdom and New Zealand: ‘Letting Go’ of the Biomedical Model of Care in Order to Develop a Contemporary *Ars Moriendi*,” *Societies* 8, no.65 (2018): 2, <https://doi.org/10.3390/soc8030065>.

home setting, in view of the emphasis that is placed on symptoms and disease rather than on the individual as a whole.

1.1.2 Technological Imperative

The term technological imperative¹⁷ denotes the enthusiasm by which technology is used in health care.¹⁸ Thus, with all its implications both on the professional and on the patient, technological imperative, may be considered as a consequence of medical technology. With the advent of technology, healthcare professionals felt duty-bound to use every available means to save the patient's life at all costs. The goals of healthcare changed from caring to curing, thus dying in the hospital setting was now being viewed as a failure rather than as a natural process. Philosopher Daniel Callahan summarises this reality thus:

There is the belief that all medical progress and research are good and, more than that, morally obligatory; that death is and always ought to be the chief enemy of medicine; that the whole point of medical technology is to use it; and that it is better for physicians to do all they can to preserve life when still more could be done, save for the last two minutes, even though all realistic hope had been given up days or weeks ago; and that in the tension between peacefully accepting death and courageously fighting to the last breath, it is best to admire the latter.¹⁹

Therefore, Callahan identifies the physicians' perceived moral obligation as the driving force behind the use of technology even in cases when there is no hope for recovery. The time spent trying to rescue a person from an inevitable death, could be better invested into focusing on the meaning the transition from living to dying has for the

¹⁷ "This term was coined by economist Victor Fuchs (1968) to describe the tendency within medicine to prioritise the development and use of new technologies regardless of their cost." See, Jill A. Fisher, and Torin Monahan, "The "Biosecuritization" of Healthcare Delivery: Examples of Post-9/11 Technological Imperatives," *Social Science & Medicine* 72 (2011): 546.

¹⁸ Bjorn Hofmann, "Is There a Technological Imperative in Health Care?" *International Journal of Technology Assessment in Health Care* 18, no.3 (2002): 679.

¹⁹ Daniel Callahan, "US Healthcare: the Unwinnable War Against Death," *Health Economics, Policy and Law* 7 (2012): 464.

person.²⁰ Time and effort should therefore be dedicated to providing comfort care,²¹ that includes the emotional and spiritual dimensions of the person, family, and significant others. Irrespective of the extent of trust that societies, professionals and patients alike place into technology's capacities in prolonging life, or rather in prolonging the dying process, "technology does not enable us to face our fears or confront what unsettles us about death."²²

1.1.3 Cascade Effect

The indiscriminate use of technology combined with the technological imperative in caring for the dying, might give rise to another troublesome concept: the cascade effect or cascade of interventions. A cascade effect is initiated with an event which in turn, leads to other events, a progression which consequently becomes difficult to halt.²³ In caring for the dying, the cascade effect can be translated into useless investigations, prescription of antibiotics, surgery, and admission to Intensive Care Unit, amongst other possibilities. In the care of the dying, the cascade effect through futile interventions is perhaps the most familiar and which possibly leaves the most harmful effects on the patient.²⁴ An important notion is that the cascade effect may also be a result of the perceived inferiority of conservative treatment,²⁵ coupled with the idea that the more

²⁰ Ira Byock, *Dying Well: Peace and Possibilities at the End of Life* (New York: Penguin Puntam Inc, 1998), 181.

²¹ "Comfort care is defined as a patient care plan that is focused on symptom control, pain relief, and quality of life. It is typically administered to patients who have already been hospitalized several times, with further medical treatment unlikely to change matters", Crossroads Hospice and Palliative Care, accessed July 17, 2021, <https://www.crossroadshospice.com/hospice-resources/hospice-caregiver-support/what-is-comfort-care/>.

²² Lydia S. Dugdale, "Dying, a Lost Art," in *Dying in the Twenty- First Century. Toward a New Ethical Framework for The Art of Dying Well*, ed. Lydia S. Dugdale (Cambridge, MA: The MIT Press, 2017), 4.

²³ Richard A. Deyo, "Cascade Effects of Medical Technology," *Annual Review Public Health* 23 (2002): 23.

²⁴ *Ibid.*, 29.

²⁵ Conservative treatment is understood as the therapeutic approaches that are limited, gradual, or well-established as opposed to radical methods, Medical Dictionary Online, accessed July 11, 2021, <https://www.online-medical-dictionary.org/definitions-c/conservative-treatment.html>.

knowledge the better.²⁶ There is a great need that professionals, patients, and society at large, understand and acknowledge that “newer and more”²⁷ in terms of technology, do not necessarily equate to better care.

Since technology started diffusing into other aspects of everyday life, the advent of medical technology was a natural progress in the healthcare setting. Medical technology gave hope for an enhanced quality of life to those who required it. However its use at the end of life is many times unjustified and conversely might be a cause of suffering for the dying person. Medical technology gave rise to new bioethical dilemmas which are at times difficult to fully comprehend and thus to resolve. Also, the influence of medical technology is considered a central cause of why death has become medicalised and thus shifted to the hospital setting. However, medical technology does not exist in a vacuum; other factors such those of a socio-economic nature are likewise believed to have influenced this shift.

1.2 Socio-Economic Influences

Caring for the sick and tending for the dying were historically the prerogative of families and communities at large. In this scenario, the words ‘community’ and ‘family’ can be considered as verbs rather than nouns²⁸ since they describe the epitome of doing and a sense of caring for others.

Since society is not static and thus prone to constant changes, cultures and rituals including those related to life and death, are bound to change too. It has been well established that the view and interaction with death and dying is affected by cultural

²⁶ Deyo, “Cascade Effects,” 33.

²⁷ *Ibid.*, 40.

²⁸ Byock, *Dying Well*, 96.

factors,²⁹ including the family's role, the meaning and purpose of life, the afterlife, and bereavement rituals. Personal understanding(s) of various issues maybe influenced and at times directly impacted by global events such as wars, pandemics, and progress including in the medical and healthcare-related fields.

1.2.1 The Industrial Revolution

One such event, the Industrial Revolution, is considered to be a main contributor of the significant changes in the structure of families and communities,³⁰ which further facilitated the process of dying out of the home. This is due to some important changes, including the migration of people from rural areas towards more urbanised ones with the aim of being engaged in higher income jobs. As a result, families were becoming smaller and thus, less family members were available to provide care within the family in times of need. The common practice whereby the young took care of their elderly relatives, usually living under one roof or in close proximity, was dwindling. To this effect, it is suggested that "before the 20th century people were less likely to die alone because they did not so often live alone."³¹

The Industrial Revolution also impacted healthcare in terms of new discoveries, evidenced based practice, and novel medical interventions which positively impacted mortality rates most notably in relation to communicable diseases.³² However,

²⁹ Charles A. Corr and Donna M. Corr, "Culture, Socialization, and Dying," in *Handbook of Thanatology: The Essential Body of Knowledge for the Study of Death, Dying, and Bereavement*, ed. David Balk (Kentucky: Routledge, 2007), 5.

³⁰ Lysaught, "Ritual and Practice," 74.

³¹ Camilla Zimmermann and Gary Rodin, "The Denial of Death Thesis: Sociological Critique and Implications for Palliative Care," *Palliative Medicine* 18 (2004): 126.

³² Communicable diseases are caused by bacteria, viruses, parasites and fungi that can be spread, directly or indirectly, from one person to another. World Health Organization Africa, accessed July 30, 2021, <https://www.afro.who.int/health-topics/communicablediseases#:~:text=Overview,ingesting%20contaminated%20food%20or%20water.>

philosopher and sociologist Ivan Illich argues that “medical interventions have not affected the mortality-rates: at best they have shifted survival from one segment of the population to another.”³³ In fact, people were now living longer but this did not automatically equate to an optimal quality of life. A surge in chronic³⁴ and degenerative³⁵ diseases gave way to new challenges which mainly revolved around the caring responsibilities of an ever-ageing, chronically ill population. Naturally, as a result, hospitals were being sought as an alternative place of care and of dying, an event which theologian M. Therese Lysaught described as a change in the “geography of dying.”³⁶

By taking the dying out of the home death was removed “out of public sight,”³⁷ and “the dying and the dead were now *stored* in new *warehouses* - nursing homes, hospitals, sealed-off mortuaries, and later hospices - inaccessible to most outsiders.”³⁸ At face value, this description emits a picture of a degrading and inhumane situation. In his depiction, sociologist Michael Hviid Jacobsen might have been referring to the actual physical separation from the sick and dying. Also, access and time family members were allowed with the dying person became limited by structured visiting hours imposed by the said institutions. This contrasts significantly to the unlimited access and time family and friends could have with a dying person at home.

³³ Illich, “Medical Nemesis,” 921.

³⁴ Chronic diseases are defined broadly as conditions that last one year or more and require ongoing medical attention or limit activities of daily living or both, National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), accessed July 30, 2021, <https://www.cdc.gov/chronicdisease/index.htm>.

³⁵ A disease in which the function or structure of the affected tissues or organs changes for the worse over time, National Cancer Institute, accessed July 30, 2021, <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/degenerative-disease>.

³⁶ M. Therese Lysaught, “Ritual and Practice,” in *Dying in the Twenty- First Century*, 73.

³⁷ Michael Hviid Jacobsen, ““Spectacular Death” – Proposing a New Fifth Phase to Phillipe Ariès’s Admirable History of Death,” *Humanities* 5, no.19 (2016): 6

³⁸ *Ibid*, (emphases added).

Together with the proliferation of hospitals and other care institutions, “the rapid and radical economic transformation that occurred at the end of the eighteenth century,”³⁹ was an “invisible cause”⁴⁰ for the transformation of the dying process.

1.2.2 A Tamed Death

Since death and dying were removed from the public’s domain, society’s portrayal of death and dying was bound to be impacted. The impact was of such an extent as to transform death and dying from a common subject of discussion into a taboo, a notion which is believed to have been pioneered by anthropologist Geoffrey Gorer⁴¹ back in 1955. Gorer considered refraining from discussing death as dangerous and even morally *wrong*.⁴² All these changes in structure and thoughts are a paradoxical paradigm to Ariès’s description of a tamed death.⁴³

Ariès describes the tamed death as a public event in which people were free to visit the dying person in his home and pay their last respects. It was also a means to support the bereaving family members and thus reinforce the community’s understanding of solidarity. The family, including children, would be present – a far cry from the contemporary situation in which children are ‘protected’ or even “disenfranchised”⁴⁴ from all that is related to death and dying. The dying person would have had control of the situation and would have known the rituals which would accompany him or her in the transition from life to death. Rituals are considered “powerful” as they encompass

³⁹ Lysaught, “Ritual,” 75.

⁴⁰ *Ibid.*

⁴¹ See, Geoffrey Gorer, “The Pornography of Death,” *Encounter* (October 1955): 49-52, accessed July 5, 2021, <https://www.unz.com/print/Encounter-1955oct-00049/?View=PDF%3E>.

⁴² Camilla Zimmermann and Gary Rodin, “The Denial of Death Thesis,” 122.

⁴³ Ariès, *Western Attitudes*, 14.

⁴⁴ Roberta Attard, “Don’t Say the “D” Word: Talking About Death and Dying With Young Children,” (paper presented at the *Hospice Biennial Conference on Palliative Care*, Qawra, April 24, 2022).

“multiple levels of meaning in a simplified symbolic form.”⁴⁵ Death rituals were important for a community as through rituals the community could “express and strengthen social cohesion,”⁴⁶ and also because “rituals stabilized a community after a crisis such as death.”⁴⁷ However, it is becoming more difficult to discern the ‘place of ritual’ in today’s societies⁴⁸ since death has been transformed into a medical event.

Ariès’s description of a tamed death was often critiqued as it was considered too romantic and too perfect. This critique can be somewhat justified since people used to die as a result of pestilence, wars, famine, and injury amongst other causes, and not only in the comfort of one’s family bosom. Also, death is never a happy event, a situation which gives rise to a myriad of emotions, questions, spiritual distress, and fear. In fact, Byock describes the dying experience as a “dark, foreboding place” which leads to an “unknown, terrifying terrain.”⁴⁹ However, rather than the dying process *per se*, perhaps what Ariès was describing was the way in which families and society at large spoke about death, accepted the process of dying, and how the said process was embraced as an integral part of everyday life. This hugely contrasts to considering death and dying a taboo in a death-denying society.

⁴⁵ Henry Fersko-Weiss, *Caring for the Dying: the Doula Approach to a Meaningful Death* (Great Britain: Orion Spring, 2017), 169.

⁴⁶ Jyrki Nissi, “Communal Acts in the Process of Death: a Comparison Between Nordic and South European 15th-century Hagiographic Material,” *Scandinavian Journal of History* 46, no. 2 (2020): 156, doi: 10.1080/03468755.2020.1808526.

⁴⁷ *Ibid.*

⁴⁸ Lysaught, “Ritual,” 68.

⁴⁹ Byock, *Dying Well*, 34.

1.2.3 A Mediated Death

It can be argued that we have moved beyond the notion of considering death a taboo and that society is death-denying, since we are consistently being exposed to death and dying through a multitude of media platforms, hence, a mediated death.

Mediated death refers to the “televisual, cinematic, and journalistic image and narrative”⁵⁰ of death. Scenes of death and dying are incessantly broadcast through televised hospital dramas, crime, forensic, and discussion programmes. Also, live broadcasting of major disaster incidents in which people are injured or dead, are instantly accessible to millions of people around the globe. But do these visual and virtual ‘accessibilities’ to death and dying translate into an understanding, acceptance, and preparedness for when dying hits home? Is this accessibility equivalent to reality? Cultural sociologist Margaret Gibson answers these questions in one word; “illusion.”⁵¹ She further argues that “the proliferation and accessibility of death imagery and narratives does not necessarily mean that the Western world has moved forward and beyond death denial.”⁵²

Since many people no longer experience the dying process at first hand, “people rely on various media, among other things, for information, attitudes, beliefs and feelings about death and its meanings.”⁵³ This scenario is described by Hetzler and Dugdale:

Depictions of trauma patients in the television show(s) might create false expectations among a general audience. These portrayals contribute to a misguided belief among the general public that medicine always has the ability to cure, fix, and save lives, regardless of

⁵⁰ Margaret Gibson, “Death and Mourning in Technologically Mediated Culture,” *Health Sociology Review* 16 (December 2007): 415.

⁵¹ *Ibid.*, 419.

⁵² *Ibid.*, 415.

⁵³ Juanne Nancarrow Clarke, “Death Under Control: the Portrayal of Death in Mass Print in English Language Magazines in Canada,” *Omega* 52, no.2 (2005-6): 154.

the type of injury or illness—precisely the sort of medicine that makes for exciting television.⁵⁴

It can be safely deduced that the reliance on media can harbour unrealistic expectations on the physician's abilities and technology to always be able to save lives and postpone death indefinitely, ergo, a demand for technology.

1.2.4 A Demand for Technology

In section 1.1, the use of medical technology by professionals in the care of the dying was discussed. At the advent of technology, there was an outcry from the public on technology's incessant, and at times unjustified use; a situation which effectively gave birth to bioethics. The predominant ethical concern was on "how to free dying patients from the unnecessary suffering and degradation caused by the overuse of life-sustaining technologies."⁵⁵ By time, an interesting shift took place: patients and their families were the ones asking for more treatment, more therapies, and more possibilities for situations wherein they would not have benefitted. Thus, patients were becoming an "active force"⁵⁶ which consequently increased the demand for technology. Thus, dying in the hospital replaced dying at home for the simple reason that the "hospital became the place to receive care which could no longer be given at home."⁵⁷

This is a common reality which the author, in her professional capacity, frequently experiences. Watching a patient afflicted with a malignant disease, who perhaps has only weeks left to live, ask for more treatment options with the hope that this time round 'it will work,' is quite a common occurrence. It also happens that family members

⁵⁴ Hetzler and Dugdale, "How Do Medicalization," E767.

⁵⁵ Farr A. Curlin, "Hospice and Palliative Medicine's Attempt" (see Introduction n. 3), 49.

⁵⁶ Cassell, "The Sorcerer's Broom," 37.

⁵⁷ Ariès, *Western Attitudes*, 87.

urge a dying relative to seek multiple medical opinions and alternative treatment options so as not to 'give up fighting.' Fight what? Perhaps as Callahan suggests, "we believe as a general value that one ought, with spirit, to fight death."⁵⁸

It is understandable that everyone hopes for a cure for oneself or a loved one, but no matter how hard we try, cure is not always possible. This remains a painful reality which is many a time difficult to comprehend and accept. There is a need for patients, families, and society alike to understand "that medicine cannot, in the end, save us from death, and thus not to expect medical miracles."⁵⁹ Callahan further argues that:

It will require a medical industry that understands that new and updated technologies that do no more than extend life for a few months (or maybe even for a year or so) at a high cost offer no real benefit. They not only can add to unsupportable health care costs but also serve to add a reason – a tantalizing seduction in fact – to put off good end-of-life care: do not give up just yet, fight the good fight.⁶⁰

As Callahan rightly observes, the use of technology in the care of the dying puts more pressure on the already exuberant healthcare expenses and limited resources. Contrary to a general assumption, healthcare resources in terms of infrastructure, finances, equipment, and human are not infinite. It has been well established that home-based end of life care is less expensive than in a hospital setting,⁶¹ since it is more supportive rather than invasive in nature. Caring for the dying in a hospital setting is much more complex and expensive since the dying person is stripped of his dying role⁶² and thus subjected to unnecessary investigations and therapies as though a cure and not death, is unavoidably the ultimate outcome.

⁵⁸ Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death* (Washington DC: Georgetown University Press, 2000), 51.

⁵⁹ Callahan, "US Healthcare," 463.

⁶⁰ *Ibid.*

⁶¹ Irene J. Higgins *et al.*, "Do Social Factors Affect Where Patients Die: An Analysis of 10 Years of Cancer Deaths in England," *Journal of Public Health Medicine* 21, no. 1 (1999): 26.

⁶² Lysaught, "Ritual and Practice," 72.

Structural changes in families and society, combined with an ever-increasing ageing population, played a major role in the shift of dying to the hospital setting. The way people viewed and dealt with death and dying has over the years changed and with it the value that one places on life itself. These changes paved the way for new bioethical dilemmas of a polarised nature; the postponement of death at one end, and the wish to hasten death on the other.

1.3 Postponement of Death and the Wish to Hasten Death

The belief that the hour of death can be controlled has become hugely ingrained in the understanding of death and dying. The moment and the manner of dying are at times a tangle of medical, personal, ethical, social, political, and religious dilemmas and confrontations. Controlling death is sought by the wish to postpone, or else to hasten the dying process. The in-between - embracing death at its own time - seems to have lost its natural place as the eventual reality for every human being. This section will deal with the possible reasons behind the wish to postpone or to hasten death which are linked with the issues discussed in 1.1 and 1.2.

1.3.1 Autonomy and Human Rights

Since care of the dying was shifted to the hospital, people started to question the care which they received or which was denied. Hence, over the past 50 years or so, healthcare options started to be discussed in terms of autonomy and human rights, including the right to die on one's own terms. To this end, autonomy with all its real or perceived meanings, was and remains one of the most prevailing and debatable arguments in end of life care. It is suggested that there may be more than one form of autonomy which ultimately aim to control death - the wish to prolong life at all costs

and the hastening of death through euthanasia, possibly as a reaction to the prolongation of life.⁶³

Autonomy remains the core argument for the proponents of euthanasia since it is argued that a person, as a rational agent, is free and has the right to choose when and how to end one's life. This stance has been debatable for centuries. For example, Hippocrates (c. 460 BC – 377 BC), considered the father of medicine, had stated that; "I will neither give a deadly drug to anybody if asked for it, nor will I make any suggestion to this effect."⁶⁴ On the other hand, the empirical philosopher of the Enlightenment era, David Hume (1711–1766), argued that euthanasia "is an appropriate way to die in the face of a dreadful disease which makes life an unfortunate circumstance not worth preserving."⁶⁵ To date, similar arguments abound and thus, autonomy related to end of life decisions remains a subject of contention.

Unlike the notion of death being a taboo subject as previously discussed, death and dying started to gain prominence, but mostly in terms of human rights. This new prominence may give the impression that death was to a certain extent brought "out of the closet."⁶⁶ However, this did not equate to discussing and recognising our finitude, our acceptance that ultimately, at some point, our days will have to come to an end and on how best to prepare for this reality.

⁶³ Autumn Alcott Ridenour and Lisa Sowle Cahill, "The Role of the Community," in *Dying in the Twenty-First Century*, 11.

⁶⁴ John D. Papadimitriou *et al.*, "Euthanasia and Suicide in Antiquity: Viewpoint of the Dramatists and Philosophers," *Journal of the Royal Society of Medicine* 100 (2007):27.

⁶⁵ Jonathan Micieli, "Hume vs. Kant on Physician-Assisted Suicide: The Death With Dignity Act," *University of Toronto Medical Journal* 83, no. 3 (2006): 199.

⁶⁶ Daniel Callahan, *The Troubled Dream of Life*, 35.

As Callahan observes, death “was put into the courtroom, turned into a matter of grand human rights.”⁶⁷ This led to a situation by which several high-profile court cases which revolved around end of life issues, made it to the headlines in view of the myriad of legal and ethical issues they amassed. As a result, people started discussing and offering opinions on individual court cases. However, discussing death as a natural progression of life remained pretty much shunned. The reason for this might be related to what Zimmerman and Rodin rightly observe that is “death in the abstract, however, remains easier to discuss than one’s own death or the death of a close friend, a relative, or a patient one has cared for.”⁶⁸

1.3.2 Dysthanasia and Euthanasia

The terms dysthanasia⁶⁹ and euthanasia,⁷⁰ are frequently confused, used interchangeably, or in the wrong context giving rise to confusion, misunderstandings, misuse, and abuse. Ana Goreti Oliveria Feio and Clara Costa Oliveria offer a similar opinion in that “the balance between not killing and not postponing death is fragile and that dysthanasia and passive euthanasia have been often confused.”⁷¹ They also argue that “although less disseminated than euthanasia, dysthanasia is, albeit unconsciously, most practiced. One anticipates the death of a person still alive and the other extends the life of a person already dead.”⁷² Thus, seriously debating and explaining these

⁶⁷ *Ibid.*

⁶⁸ Zimmermann and Rodin, “The Denial,” 123.

⁶⁹ “Dysthanasia is an attempt to maintain life at any cost, with disproportionate medical acts that make death difficult, with no real prospect of recovering life and well-being.” Carlos Wilson de Alencar Cano *et al.*, “End of life: Conceptual Understanding of Euthanasia, Dysthanasia and Orthothanasia.” *Revista Bioética* 28, no. 2 (2020): 377, doi: 10.1590/1983-80422020282399.

⁷⁰ Euthanasia, *a good death*, is an umbrella term which encompasses several options to end a person’s life at his or her request.

⁷¹ Ana Goreti Oliveira Feio and Clara Costa Oliveira, “Responsibility and Technology: The Issue of Dysthanasia,” *Revista Bioética* 19, no.3 (2011): 618.

⁷² *Ibid.*, 615.

possibilities would require a deeper understanding of the underpinnings and implications of each individual issue.

As of late, a problematic and misguided idea that euthanasia can be a semblance of palliative care is being fostered especially in countries where euthanasia is legalised. On the one hand, this situation requires serious considerations since its implication(s) might negatively impact genuine palliative care.⁷³ On the other hand, it might be implicated that the pressure to legalise euthanasia stems from the lack of adequate palliative care⁷⁴ and other support measures including community and hospice care.

Contrary to what might be a common belief, patients receiving hospice care are amongst those who ask for extraordinary measures of care and euthanasia.⁷⁵ Terminally ill patients receiving home hospice care are three times more likely to ask for hastening of death than patients in other caring institutions.⁷⁶ The author of this dissertation has experienced instances wherein a patient or a relative raised the subject of euthanasia and that if it was legal, they would consider it. Requests for euthanasia in the home setting are considered as a 'cry for help' and may stem from the fear of poor quality of life, of being a burden on the family, of being abandoned, and of becoming dependent

⁷³ COMECE, "Opinion of the Working Group on Ethics in Research and Medicine on Palliative Care in the European Union," (2016): 25, accessed July 20, 2021, http://www.comece.eu/dl/uuomJKJKooNMJqx4KJK/PalliativeCARE_EN.pdf.

⁷⁴ See, for example, Pierre Mallia, "Proper Palliative Care Needs to be Improved Before Considering Euthanasia," *The Malta Independent*, August 15, 2021, <https://www.independent.com.mt/articles/2021-08-15/local-news/Proper-palliative-care-needs-to-be-improved-before-considering-euthanasia-6736235973>.

⁷⁵ Elizabeth Mayfield Arnold, Katherine Abbott Artin, Judi Lund Person, and Devin L. Griffith, "Consideration of Hastening Death Among Hospice Patients and Their Families," *Journal of Pain and Symptom Management* 27, no.6 (2004):524.

⁷⁶ *Ibid.*

and thus losing dignity.⁷⁷ These realities may consequently become a cause of great distress and suffering.

Distress, as Eric Cassell suggests, “occurs when the intactness or integrity of the person is threatened or disrupted.”⁷⁸ The integrity of a person remains valuable till the very end. A dying person risks to be treated as if he or she is already dead - a body - rather than a person who is going through the dying process. The uncertainty by which a dying person is to be cared for might be a result of placing more importance on curing rather than caring, whilst providing quality end of life care and adequately addressing pain and suffering, remain in the margins of the healthcare system.

1.3.3 Pain and Suffering

Despite great leaps in medicine and healthcare provisions, pain and suffering remain major challenges in end of life care. Since every individual reacts differently to pain control measures, converging the right balance of providing effective pain relief without prejudicing the person’s quality of life, and at the same time respecting a person’s beliefs, is at times hard to achieve.

Considered as a *locus classicus*, Eric J. Cassell’s work “The Nature of Suffering and the Goals of Medicine,”⁷⁹ highlights the differences between pain and suffering which many a time are considered one and the same. This differentiation is imperative in order to better understand and appropriately respond to a person’s experience of pain and suffering. A similar observation is offered by Lynn A. Jansen and Daniel P. Sulmasy who

⁷⁷ *Ibid.*, 528.

⁷⁸ Eric J. Cassell, “Diagnosing Suffering: A Perspective,” *Annals of Internal Medicine* 131, no. 7 (1999): 531.

⁷⁹ See, Eric J. Cassell, “The Nature of Suffering and the Goals of Medicine,” *The New England Journal of Medicine* 306, no. 11 (1982): 639 – 645.

state that differentiating between *neuro-cognitive suffering*⁸⁰ and *agent-narrative suffering*⁸¹ is a possibility even if at times it is difficult to achieve. The difficulty to differentiate between pain and suffering is related to the personal understanding, meaning, and value which remain unique to every individual.

A common assumption amongst health care providers, is that if patients state that they are not in pain, it automatically means that they are comfortable.⁸² Suffering may be present in the absence of physical pain and can manifest itself under different guises. Suffering is mostly related to feelings, emotions, and even faith. Thus, it can take the form of an emotional, psychological, spiritual, and also existential distress – all too common in a dying process.

The manner in which pain, suffering, and the actual death process are addressed may differ between the hospital and home setting for several reasons. Central to these remains the available time professionals have with patients and their families, necessary to foster a therapeutic relationship.⁸³ In the hospital setting, the care of a dying person might be considered a routine, part of the day-to-day running of the ward. At times, a dying person is “isolated from other patients,”⁸⁴ a situation which may impact on the

⁸⁰ “Neuro-cognitive suffering is described as suffering that has a direct causal relationship to the patient’s underlying medical condition.” See Lynn A. Jansen and Daniel P. Sulmasy, “Proportionality, Terminal Suffering and the Restorative Goals of Medicine,” *Theoretical Medicine* 23 (2002): 324.

⁸¹ “Agent-narrative suffering is described as suffering that has an indirect causal relationship to the patient’s underlying medical condition. It is not the medical condition as such that causes the patient to suffer, but it may arise from the patient’s beliefs about what the condition means or will mean for his or her life.” *Ibid.*, 325.

⁸² Barry K. Baines and Linda Norlander, “The Relationship of Pain and Suffering in a Hospice Population,” *American Journal of Hospice & Palliative Care* 17, no. 5 (2000): 325.

⁸³ Therapeutic relationship include personal awareness and insight, trust, respect, safety, authenticity, acceptance, empathy, and collaborative agreement, “Therapeutic Relationship,” accessed September 27, 2021, <https://medical-dictionary.thefreedictionary.com/therapeutic+relationship>.

⁸⁴ Emmanuel Agius, “The Rights of the Dying Patient,” in *Bioethical Issues at the Beginning and End of Life: Proceedings of The Conference Organised by the Bioethics Consultative Committee*, ed. M.N. Cauchi (Malta: Government Press, 2002), 142.

person's dignity.⁸⁵ This might lead to situations in which the dying patient's needs are not identified and adequately addressed, which conversely may give way to what is described as 'nosocomial dysthanasia.'⁸⁶ For example, it would be futile to increase a prescribed opioid dose as a patient's pain seems to be uncontrolled when in reality what one would require is emotional, spiritual, or any other kind of support beyond the physical. Relatives are rarely allowed to stay beyond the visiting hours, a situation which may foster a sense of abandonment and loneliness. It also robs the patient and his or her family from precious time together which may translate into a missed opportunity to say their final goodbye.

Caring for the dying at home⁸⁷ through hospice palliative care, focuses on the personal aspects rather than on futile medical procedures. It seeks to nurture a therapeutic relationship based on communication and mutual respect with the patient and his or her family. Communication is a continuous process all through the trajectory of the disease and beyond. A thorough primary assessment of the patient and his or her particular circumstances which includes the physical, emotional, spiritual, financial, and also logistical, is carried out and is periodically reviewed. This will enable the hospice team to plan and adjust a personalised care plan with the aim of addressing the patient's needs which change, at times, at very short intervals.

Effective pain and symptom management, and the alleviation of suffering, remain perhaps the primary concerns on the patient's mind when one is referred to hospice

⁸⁵ *Ibid.*

⁸⁶ Charlie Corke, William Silvester and Rinaldo Bellomo, "Avoiding Nosocomial Dysthanasia and Promoting Eleoethanasia," *Critical Care and Resuscitation* 12, no. 4 (2010): 221.

⁸⁷ Hospice care can be provided at a patient's own home, long term facilities, nursing homes, convents, and other dwellings which are considered as the usual place of residency for a patient. For the purpose of this study, home refers to a patient's own house.

palliative care. Contrary to a pervasive notion, if the appropriate support in terms of resources⁸⁸ and team effort are established, pain and symptom management in the home setting is possible and is many a time effective. Hence, dying at home becomes a possibility. In this scenario, unnecessary admission of the dying person to the hospital may be avoided. Consequently, seeking medical possibilities as means to an undignified prolongation of life or the hastening of death, may be diminished or circumvented.

1.4 Conclusion

This chapter has sought to articulate some factors which are considered to have impacted the shift of dying from the home to the hospital setting. Although by no means exhaustive, medical technology and socio-economic factors were identified as two primary factors which literature suggests might have led to this shift. This chapter has also sought to shed light on the possible reasons behind a request for the postponement of death or for hastening death. It has been argued that behind these requests is a cry for help to put an end to a situation which has become unbearable and is a cause for pain and suffering. The postponement and hastening of death became an option since death has been transformed into a medical event in a hospital setting and no longer viewed as a natural process in one's home or community. The next chapter will thus consider care ethics as an ethical framework and the similarities it shares with hospice palliative care as a response to the state of affairs just described.

⁸⁸ Resources, here, refer but are not limited to specialised equipment, access to drugs, community nursing services, general practitioner's input, after-hours support, and adequate housing conditions.

Chapter Two: Considering Caring for the Dying at Home as Care Ethics

Often times, bioethics, is largely equated to principlism - the four-principle approach - autonomy, non-maleficence, beneficence, and justice - described by Tom Beauchamp and James Childress in 1979.¹ Principlism views the individual as a rational, independent, and autonomous being. While it is true that principlism has its strengths, and that it has helped solve bioethical dilemmas for decades, it can be considered too individualistic in instances when the reliance on others is a central element of care. Thus, in principlism, the reality of the individual as a dependant being and the “morality for which it calls,”² is mostly unconsidered.

Caring for the dying at home differs from the hospital setting for a multitude of reasons, which primarily revolve around the question of ‘who is in charge’ of the care to be given. In the hospital setting, the physician and his or her team are in charge, whilst in the home setting, it is the patient and his or her family who decide, accept, or refuse the care and related interventions suggested. It is argued that “although patients can refuse treatment in any setting, this refusal carries more conceptual and practical weight on the patient’s home turf,”³ since health care providers may be considered as ‘guests’ invited into the home under special circumstances. Thus, principlism, which is generally appropriate for the hospital setting, might not be the most suitable ethical framework

¹ John-Stewart Gordon, “Bioethics,” Internet Encyclopaedia of Philosophy, accessed September 30, 2021, <https://iep.utm.edu/bioethic/>.

² Held, *The Ethics of Care*, (see Introduction, n.5), 10.

³ Edward R. Ratner, and John Y. Song, “Ethics and Dying at Home,” *Home Health Care Management & Practice* 15, no. 2 (2003): 124.

by which moral quandaries pertinent to the home setting are addressed. To this end, Ratner and Song suggest that:

What might be required are different moral frameworks and guidance such as that provided by the feminist-inspired theories of ethics of care. With these theories, the locus of morality focuses on these interpersonal relationships and the context of decision making, a more harmonious framework to home-based care than principlism.⁴

This chapter will hence consider care ethics and the similarities it shares with hospice palliative care philosophy, as a response to the state of affairs described in chapter 1. It will be divided into three sections, in which three of the five major features of ethics of care as defined by Virginia Held will be evaluated. Held lists these features as follows: (1) the moral prominence of responding and attending to the needs of others, (2) emotions as an embraced rather than a rejected value, (3) the rejection of the view that the reasoning of moral issues should be in the abstract, (4) care as both a private and a public value, and (5) the concept of a person as a relational rather than a self-sufficient, independent being.⁵

Section one will look into the moral prominence of responding and attending to the needs of others. Section two will focus on the value of emotions, which care ethics embraces rather than rejects. In section three, care as a value both in the personal and public spheres will be addressed. Although the concept of a person as a relational - rather than a self-sufficient and independent being - was originally proposed to be included in this work, the author feels that since it is closely interrelated to the previous three features, it will be omitted.

⁴ Ratner and Song, "Ethics and Dying," 124.

⁵ Held, *The Ethics of Care*, 9-13.

2.1 The Moral Prominence of Responding and Attending to the Needs of Others

Care ethics is described as a “specific moral perspective that reads moral questions in terms of responsibilities and that is concerned more about the dangers of abandonment than the dangers of interference.”⁶ Therefore, care ethics seeks to place value on relationships, presence, and responsibilities through which the needs of those who require care are responded to. Similarly, the ethos of hospice palliative care is based on the values of “relief from suffering, commitment to presence and non-abandonment, and quality of life lived in and through the dying process.”⁷ Both philosophies emphasise the responsibility of being present and of caring for others, which stems from the caring disposition inherent to human beings.

Philosopher Nel Noddings, a pioneer in care ethics, considers “motherhood as the starting point for ethics.”⁸ Electing the word motherhood can be attributed to the fact that motherhood is considered selfless, the most natural of care, which generally, is bestowed from a mother onto her child. This reflection, however, is subject to criticism based on the argument that the responsibility to care for those considered as ‘strangers,’ is not addressed. A counterargument is that the nursing profession is based on care ethics, and nurses and other healthcare professionals, including Hospice’s interdisciplinary team, primarily take care of people whom they do not know.

⁶ Marian A. Verkerk, “Care Ethics as a Feminist Perspective on Bioethics,” in *New Pathways for European Bioethics*, eds. Chris Gastmans, Kris Dierickx, Herman Nys, and Paul Schotsmans (Antwerp, Belgium: Intersentia, 2007), 65.

⁷ Timothy W. Kirk and Bruce Jennings, “Introduction,” in *Hospice Ethics: Policy and Practice in Palliative Care*, eds. Timothy W. Kirk and Bruce Jennings (New York: Oxford University Press, 2014), 2.

⁸ Amy M. Haddad, “Care Ethics,” in *Encyclopedia of Global Bioethics*, ed. Henk ten Have (Cham: Springer, 2016), 435, doi: https://doi-org.ejournals.um.edu.mt/10.1007/978-3-319-09483-0_69.

Steven D. Edwards, professor of nursing philosophy, proposes that since historically, medicine and nursing were gender-defined, i.e., medicine is male and nursing is female, it was commonly accepted that principlism is more adept to the medical profession, whilst care ethics was more appropriate for the nursing practice.⁹ This gender-based view reflects another common criticism to which care ethics is subjected, i.e. that it is an ethics only for women. Joan C. Tronto, professor of political science, tends to differ from this view, as she describes care as “a *species activity* that includes everything that we do to maintain, continue, and repair our ‘world’ so that we can live in it as well as possible.”¹⁰ Thereby, it can be argued that Tronto believes that everyone is morally obliged to care for others in a much broader way than exclusively within the family and private realms. This notion was also expressed by Held, who further suggested care as being a social and a political value.¹¹

Care, thus, should be more concerned with how human beings interact with each other and respond to each other’s needs in all of life’s circumstances, including in times of illness and during the process of dying. However, in order to be able to respond to the needs of others, an understanding of care and what it entails for it to be acted upon, delivered, and accepted is required. This is significant because as Held suggests, “care has many forms, and as the ethics of care evolves, so should our understanding of what care is.”¹² It is to this that we shall now turn.

⁹ Steven D. Edwards, “Three Versions of an Ethics of Care,” *Nursing Philosophy*, 10 (2009): 231-232.

¹⁰ Joan C. Tronto, “An Ethic of Care,” *Generations: Journal of the American Society on Aging* 22, no. 3
Ethics and Aging: Bringing the Issues Home (1998):16 (emphases added).

¹¹ Held, *The Ethics of Care*, 38.

¹² *Ibid.*, 29.

2.1.1 The Meaning of “Care” in Hospice Palliative Care

Defining, or rather, comprehending care and what it stands for is not easy, since it can be subject to a myriad of interpretations which may stem from socio-cultural, religious, and political influences.

Care is generically defined as “the provision of what is necessary for the health, welfare, maintenance, and protection of something or someone.”¹³ However, the understanding of care in the context of care ethics merits a deeper consideration since it is not just a noun or a verb. It is also considered an ethical concept¹⁴ which “gives expression to the values of *responsiveness* to human needs, *responsibility* and *competence* in care giving, the value of *connectedness*, and the value of care-giving.”¹⁵ Thereby, care also requires concrete action by which the needs of a person are identified and addressed, which action goes beyond “a set of principles and rules.”¹⁶ In the healthcare setting, action translates to the interdisciplinary team’s input which is a central component of hospice palliative care.

From its inception in 1967, Hospice care, attributed to Dame Cicely Saunders, sought to provide an alternative mode of care to the terminally ill and dying persons as a response to the state of affairs described in chapter 1. A dying person was viewed as a collection of medical challenges, rather than a living individual who is going through the dying process. On the other hand, Saunders considered the individual in his or her totality beyond the physical nature. She gave attention to an individual’s emotional, psychological, spiritual, and social aspects. This in view that through her work with the

¹³ “Care,” accessed October 9, 2021, <https://www.lexico.com/definition/care>.

¹⁴ Verkerk, “Care Ethics,” 67.

¹⁵ *Ibid*, (emphases added).

¹⁶ Tronto, “An Ethic of Care,” 16.

dying she recognised that, “support was needed both before and after a patient's death, particularly in home care, when the family are the central carers.”¹⁷ Thus, even if not explicitly articulated, hospice palliative care inadvertently embraces an ethics of care philosophy since it strives to be present and not to abandon the patient and his or her family through the trajectory of the disease and beyond. This correlates with the view of Verkerk who suggests that “good caring therefore involves a view on the caring relationship as an ongoing process.”¹⁸

For the outsider, it may look like Hospice interferes with the patient and his or her family. However, this is far from reality. What the hospice team strives to achieve is a sound relationship with the patient and his or her significant others, with the ultimate goal being that of attending to the needs of the patient and providing support in the midst of a hugely taxing situation. If this is interference, then it can be considered as “compassionate interference,”¹⁹ as “the carer sees the patient as someone of importance who is worthwhile standing next to.”²⁰

This *quasi* intimate care relationship tends to be lost in the hospital setting due to a multitude of factors, central to this is the disproportionate nurse/healthcare providers - patient ratio. It is argued that hospital-based care absorbs “dying people into a ‘system’ where they become processed as patients rather than individuals.”²¹ This may translate into less available time to build a meaningful caring relationship which inadvertently could affect the care outcome. Philosopher Eva Feder Kittay argues that we need “to

¹⁷ Cicely Saunders, “Into the Valley of the Shadow of Death. A Personal Therapeutic Journey,” *BMJ* 313 (1996): 1600.

¹⁸ Verkerk, “Care Ethics,” 71

¹⁹ *Ibid.*, 76.

²⁰ *Ibid.*

²¹ Susan Stringer, “Quality of Death: Humanisation Versus Medicalisation,” *Cancer Nursing Practice* 6, no. 3 (2007): 27.

gain epistemic access to another,"²² which in simpler terms means getting to know each other, which is considered essential in a caring relationship.

The hospice team accompanies the patient through his or her journey, advises when necessary but does not take over the explicit wishes of the patient in decisions that need to be taken, thus seeking to preserve a person's autonomy till the very end. Autonomy at the end of life is suggested as being "that which allows an individual to face death with integrity on his own terms,"²³ which thus includes the care to be received during the dying process.

2.1.2 The Caring Process

Since care requires action both from the caregiver and the care receiver, it is also a process which may involve several phases. For example, Professors Berenice Fisher and Joan Tronto describe four phases of the caring process; caring about, caring for, caregiving, and care receiving.²⁴ An interesting observation is that Fisher and Tronto have aptly described a moral dimension for each of the four caring phases. They suggest *attentiveness* in caring about, *assuming responsibility* in caring for, *competence* in caregiving, and *responsiveness* in the care receiving phase, as moral qualities.²⁵ In so doing, the caring process was elevated to a moral obligation and not merely a duty. Hospice palliative care in the home setting can be considered as a process which encompasses the four phases described above.

²² Eva Feder Kittay, "Caring About Care," *Philosophy East & West* 69, no. 3 (2019): 860.

²³ Michelle Harrington and Daniel P. Sulmasy, "Spiritual Preparation," in *Dying in the Twenty- First Century* (see chapter. 1, n 23):88.

²⁴ Berenice Fisher and Joan Tronto, "Towards a Feminist Theory of Care," in *Circles of Care*, eds. E. Abel and M. Nelson (Albany, NY: State University of New York Press, 1990), quoted in Tronto, "An Ethic of Care," 16-17.

²⁵ *Ibid* (emphases added).

In 'caring about,' the patient's assigned keyworker, who is generally a nurse, makes the first contact with the patient and his or her family. The patient's needs and wishes are identified by carefully listening to what the patient has to say. However, as Kittay suggests, the person receiving care may resist what she describes as "the inquiring gaze"²⁶ i.e., that the person might not want to let his or her carers know him or her. Thus, special consideration should be given to what is left unsaid as this might impact the whole caring process since knowing what care to provide, requires knowing what the person's needs are in the first instance. To this end, Saunders maintains that "for those who do not wish to share their deepest needs, the way care is given can reach the most hidden places."²⁷ This requires the caregiver to be sensitive and respectful towards how much information a patient wants to be disclosed. Also, in order for the caregiver to be able to understand the patient's needs, it requires that the caregiver is free from any biases²⁸ which can cloud his or her judgments.

This first encounter sets the stage for the 'caring for' phase. From the information that it is gathered, the keyworker is responsible to devise a care plan to address the needs identified. Other members of the hospice's interdisciplinary team, such as the physiotherapist, complementary therapist, social worker, chaplain, medical officer, and at times volunteers too, might require to be involved. The hospice care team is described as being the "vehicle through which clinicians and staff actualize their *commitment* to create plans of care."²⁹ It has been well established that caring is bound to be much more

²⁶ Kittay, "Caring About Care," 860.

²⁷ Saunders, "Into the Valley," 1601.

²⁸ Kittay, "Caring About Care," 860.

²⁹ Terry Altilio and Nessa Coyle, "The Interdisciplinary Team – Integrating Moral Reflection and Deliberation," in *Hospice Ethics: Policy and Practice*, eds. Timothy W. Kirk and Bruce Jennings (New York: Oxford University Press, 2014), 113-114 (emphasis added).

effective when it involves a team effort rather than individual input, thus staying true to a holistic approach to care.

'Caregiving' is the phase wherein the services required are being provided. This might require the input of community nursing which provide assistance in personal hygiene and preparation of prescribed drugs amongst others services. In caregiving, professional competence remains paramount since incompetency is in itself a moral problem³⁰ by which the patient can only be harmed.

'Care receiving' is the phase in which the person who is receiving care is expected to respond to the said care. An ongoing evaluation of this phase is thus essential in order to assess the degree of effectiveness of the care being given and any adjustments required are implemented. It can be argued that Kittay's observation that "caring is not about what someone does *to* another person. It is something one does *with and for* someone,"³¹ cogently sums up the caring process.

Care and the caring process are in themselves complicated, and this becomes more accentuated when factors such as a patient's denial of his or her state of health and possible impending death, challenging relationships, and service provider limitations become part of the equation. These factors are an ongoing challenge for the hospice palliative care team which unfortunately, at times, might even impact on the experience of the caregiver and the care receiver alike. Unfortunately, no matter how much the strive for a perfect caring process is, in reality this is seldom achievable.³²

³⁰ Fisher and Tronto, "Towards a Feminist Theory," quoted in Tronto, "An Ethic of Care," 17.

³¹ Kittay, "Caring About Care," 860.

³² Tronto, "An Ethic of Care," 17.

Responding to the needs of others and attending to them are a major feature of care ethics. The philosophy of hospice palliative care embraces the nature of care ethics, as it also strives to place the patient and his or her needs at the core of the care provided. Even though in the hospital setting a patient is considered to be central to care, the care received by a dying person may be fragmented. This may give rise to inadvertently overlooking the needs of the individual and responding to those needs in a timely and appropriate manner. Furthermore, both care ethics and hospice's philosophy of care exalt and attend to the emotions with which a dying process is impregnated, a value which often times is not given its merited consideration. The following section will thus discuss emotions as another major feature in care ethics.

2.2 The Value of Emotions

"How are you doing *within yourselves*?"³³ A simple question, which Dr. Ira Byock, as the caring palliative consultant, posed to the parents of a 25-year old dying man.³⁴ The author of this study feels that this question is profound, and is of the opinion that it goes far deeper than a mere 'how are you doing.' For her, 'within yourselves,' encompasses the whole extent of one's being, the meaning and value which a particular situation holds, the myriad of emotions a particular situation may institute, and maybe, the meaning of life and death itself at the moment this question was asked.

End of life care and confronting a dying process, are experiences which are imbued with emotions that can oscillate between despair, fear, grief, hope, sadness, shame and as Carlo Leget, professor of care ethics suggests, at times even joy.³⁵ All those involved

³³ Ira Byock, *The Best Care Possible* (New York: Penguin Group, 2013), 142 (emphases added).

³⁴ *Ibid.*

³⁵ Carlo Leget, "Ethics, Emotions and Culture: Respecting Moral Diversity," *Palliative Medicine* 32, no. 7 (2018): 1145.

in end of life care will at some point through the disease trajectory and even beyond, have to deal with a gamut of emotions, which at times can be overwhelming. This is inevitable, since emotions are considered integral to being human, and which tend to become more accentuated or complicated in difficult moments. However, the understanding of emotions as an essential aspect of the human species was, and is still, not always fully comprehended and thus risks to be undervalued.

2.2.1 Understanding Emotions

Emotions have been a subject of debate and contestation for millennia. For example, Plato (ca. 428-347 B.C.), described emotions as being “unwelcome distractions that clouded the clear reasoning indispensable to making good ethical decisions.”³⁶ On the other hand, Aristotle (384-322 B.C.), considered emotions as “central and essential to the good life, and the analysis of their nature is part and parcel of an ethical analysis,”³⁷ a view, which can be considered as being philosophically similar to care ethics. More recently, Held proposed that care ethics values emotions as essential to the understanding of “what it would be morally best for us *to do* and *to be*.”³⁸ This view is ostensibly dismissed by several classical ethical theories which consider emotions as being irrelevant in moral deliberation.

One of the earliest essays asking the question “*What is an Emotion?*” written by William James in 1884,³⁹ was followed by a voluminous amount of literature asking the same question, which provided a vast array of descriptions, but were unable to provide

³⁶ *Ibid.*

³⁷ Robert C. Solomon, “The Philosophy of Emotions,” in *Handbook of Emotions*, Third Edition, eds. Michael Lewis, Jeannette M. Haviland-Jones, and Lisa Feldman Barrett (New York: The Guilford Press, 2008), 5.

³⁸ Held, *The Ethics of Care*, 10, (emphases added).

³⁹ William James, “What is an Emotion?” *Mind* 9, no. 34 (1884): 188-205, accessed October 26, 2021, <https://www.jstor.org/stable/2246769>.

a comprehensive answer. An emotion is described as “a combination of an eliciting condition, a bodily state, facial and body expression, and a conscious perception,”⁴⁰ i.e. the emotional experience *per se*. However, such description fails to capture the essence of an emotion beyond its physiological manifestation.

Realistically, envisaging to describe an emotion in its totality is difficult since “emotions feel so deeply personal, and so related to our values and hopes, that it is almost impossible to convey their meaning to others in ways that can be understood.”⁴¹ In fact, Cain Todd notes that “the precise delineation of the constitutive components of emotions, and of the distinctive nature of emotional experience”⁴² have been proved to be a hard endeavour for philosophers and psychologists alike.⁴³ It might be easy to tell someone ‘I understand you,’ but in reality, no two people can ever experience a situation in the same way no matter how identical the situation is. Similarly, a caregiver can never fully comprehend a patient’s experience and the emotions it emits, no matter the wish to do so. This is because emotions do not only pertain to a present situation, but are also a tangle of remnants from past experiences.

Philosopher Martha C. Nussbaum argues that emotions have a history,⁴⁴ and that emotions “cannot be understood without understanding their history in infancy and childhood.”⁴⁵ A similar view was expressed by Swiss psychologist Jean Piaget, in 1932, in

⁴⁰ Paul Henry Mussen, John Janeway Conger, Jerome Kagan, and Aletha Carol Huston, *Child Development and Personality*, Seventh Edition (New York: Harper Collins Publishers, 1990), 410.

⁴¹ Heather C. Lench and Zari Koebel Carpenter, “What Do Emotions Do for Us?” in *The Function of Emotions. When and Why Emotions Help Us*, ed. Heather C. Lench (Cham: Springer, 2018), 1, doi: <https://doi.org/10.1007/978-3-319-77619-4>.

⁴² Cain Todd, “Emotion and Value,” *Philosophy Compass* 9, no.10 (2014): 702, doi: <https://doi.org/10.1111/phc3.12167>.

⁴³ *Ibid.*

⁴⁴ Martha C. Nussbaum, *Upheavals of Thought: The Intelligence of Emotions* (New York: Cambridge University Press, 2008), 175.

⁴⁵ *Ibid.*, 178

his book *The Moral Judgement of the Child*. Here, Piaget makes an interesting observation i.e., that “in a sense, child morality throws light on adult morality.”⁴⁶ This suggests that the way in which adults behave and respond in adulthood is influenced by their childhood experiences and the effect which they may have had on them.

Children express and experience emotions through play and conversations which thus, make them central to their life’s experience and relationship with others.⁴⁷ In caring for the dying, Saunders had recognised that “each death was as individual as the life that preceded it and that the whole experience of that life was reflected in a patient's dying.”⁴⁸ Hence, the emotional aspect of a person is bound to be influenced for a lifetime, since emotions are experienced and expressed from the very beginning through to the end of life.

Much of the literature pertaining to the description and understanding of emotions, mostly accentuate a distinction between reason and emotions. Robert C. Solomon, professor of philosophy, argues that this distinction is “as if we are dealing with two different natural kinds, two conflicting and antagonistic aspects of the soul.”⁴⁹ It can be deduced that Solomon’s argument is in principle similar to the mind-body dualism as described by philosopher René Descartes.

The mind-body dualism suggests that a person is made up of two distinct entities, i.e. the body and the mind, and which consequently, questions the relationship between

⁴⁶ Jean Piaget, *The Moral Judgement of the Child* (Oxon: Routledge, Trench, Trubner & Co., Ltd, 1932), ix, accessed November 13, 2021, https://www.burmalibrary.org/docs20/Piaget-moral_judgment_of_the_child-en-ocr-tu.pdf.

⁴⁷ Mussen *et al*, *Child Development and Personality*, 408.

⁴⁸ Saunders, “Into the Valley of the Shadow,” 1600.

⁴⁹ Robert C. Solomon, “Emotions, Ethics, and the “Internal Ought,” *Cognition and Emotion* 10, no.5 (1996): 532, doi: <https://doi.org/10.1080/026999396380141>.

the physical and the intellectual properties. Similarly, considering reason and emotions as separated, assumes that they cannot coexist in harmony. Also, Solomon argues that the distinction between rationality and emotions is a cause for “a contorted or truncated ethics falsely forced to choose between reason or sentiment.”⁵⁰ This might imply that an ethical deliberation either cannot happen in an emotionally-charged situation, or else, that emotions are to be disregarded for the sake of rationality.

Emotions have, and are at times labelled, in a variety of ways amongst which as being “impetuous, obsessive, antisocial, selfish, and even evil.”⁵¹ Labelling is mostly attached to those which are considered as ‘negative’ emotions for example; anger, frustration, and sadness. Attaching a label to an emotion may devalue its meaning for the person who is experiencing it and in so doing, the risk of becoming insensitive to the person’s plight becomes a possibility. Nussbaum argues that labelling emotions “alters the emotions we can have,”⁵² and so, the way by which emotions are experienced can be influenced by such labelling.⁵³ For example, a person who is feeling sad may not convey this feeling or tries to conceal his or her sadness from others, if in the past, this same feeling was dismissed or remained unrecognised by others. Similarly, Saunders had intuited that emotions, such as guilt amongst cancer patients, were “often imposed” on the patient by others,⁵⁴ generally, by members of the patient’s family.

Attempting to define and understand emotions was and will remain challenging. However, beyond a definition and a comprehension, as Todd suggests, “emotions arise,

⁵⁰ Solomon, “The Philosophy of Emotions,” 3.

⁵¹ Andrzej Dąbrowski, “Emotions in Philosophy. A Short Introduction,” *Studia Humana* 5, no.3 (2016): 12.

⁵² Nussbaum, *Upheavals of Thought*, 149.

⁵³ *Ibid.*

⁵⁴ Cicely M. S. Saunders, “The Care of the Terminal Stages of Cancer,” *Annals of The Royal College of Surgeons of England* 41, (1967): 164, accessed November 4, 2021, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2312282/>.

ultimately, because we care about persons, things, and states of affairs; that is, we value them.”⁵⁵ This suggestion has a twofold implication, i.e. it implies that emotions give value to caring and that emotions are valued in care and caregiving.

2.2.2 Emotions in Caregiving

Emotions are more than “noises” that trouble our cognitive processing; they create the possibility of *rational action*. Emotional responses can act as a moral compass in *responding to the other person*. Emotions, viewed in this way, signal a *response to the plight of the other* and guide perception of salient moral issues, and thus are not empty of cognitive or moral content or necessarily disruptive of reasoning processes.⁵⁶

Appraising the above epigraph, written by nursing theorist Patricia Benner, one can notice the similarities it shares with care ethics. More specifically, the reference to ‘responding to the other person’ and ‘response to the plight of the other,’ are both central to care ethics. Emotions can thus be considered as those by which the needs of others are identified and attended to through caring.

Caring for the dying brings to the fore our vulnerability, which may also prompt us to acknowledge that we are interdependent. Besides, “emotions reveal us as vulnerable to events that we do not control,”⁵⁷ and certainly, dying predominates the list of all possible uncontrollable events one can experience. However, a secular society tends to view vulnerability and interdependence with disdain. It must be acknowledged “that we live in a society that leaves less and less place for aging, frailty, illness, and death.”⁵⁸ In an era when everyone is expected to be self-sufficient, when autonomy and human rights predominate almost all debates pertaining to life and death-related issues,

⁵⁵ Todd, “Emotion and Value,” 702.

⁵⁶ Patricia Benner, “A Dialogue Between Virtue Ethics and Care Ethics,” *Theoretical Medicine* 18 (1997): 54 (emphases added).

⁵⁷ Martha C. Nussbaum, “Précis of Upheavals of Thought,” *Philosophy and Phenomenological Research* 68, no.2 (2004): 446.

⁵⁸ Eric Vermeer, “The Slippery Slope Syndrome,” in *Euthanasia: Searching for the Full Story*, ed. Timothy Devos (Cham: Springer Nature, 2021), 8, accessed August 8, 2021, <https://www.springer.com/gp/book/9783030567941>.

acknowledging that ultimately, we might require to lean on others for care and support becomes hard to acknowledge and accept.

Held suggests that what might be considered as ‘moral emotions,’ such as sympathy, empathy, sensitivity, and responsiveness,⁵⁹ which are all too common in hospice palliative care, need to be cultivated.⁶⁰ Kittay adds another dimension to the moral emotions just described, since she considers them essential in moral deliberation.⁶¹ These two observations pose a huge responsibility on the caregiver, since it can be argued that caring devoid of moral emotions renders the caring process as a mere ‘job’ rather than a moral duty which seeks to identify and respond to the needs of those under one’s care. This thus ascribes to an “emotionally engaged attention,”⁶² which is described as being “an ethical activity that depends on responsiveness to the unique particularity of another person.”⁶³ Caring in itself should thus be an emotionally-engaging activity whereby emotions are acknowledged and valued, and in which an emotional bond is fostered between the care receiver and the caregiver.

Besides the physical symptom control, attending to the emotional needs of a patient and also of his or her family, is considered as central to hospice palliative care. At times, this can be complicated and quite challenging since in dealing with emotions, the hospice team is faced with what is considered as the most intimate aspect of one’s being. Since emotions are experienced differently by different people, the value

⁵⁹ Held, *The Ethics of Care*, 10.

⁶⁰ *Ibid.*

⁶¹ Eva Feder Kittay, “The Ethics of Care, Dependence, and Disability,” *Ratio Juris* 24, no. 1 (2011): 53.

⁶² Peta Bowden, *Caring. Gender-Sensitive Ethics* (London: Routledge, 1997), 109.

⁶³ *Ibid.*

attached to them differs too. This requires one to be sensitive in attempting to comprehend and value what the patient is trying to convey through his or her emotions.

For many, giving emotional support might emit a picture of complicated psychological interventions. We tend to underestimate the power of simply listening and giving space and time for a patient to talk. Contrary to a common belief, patients do not always require their caregivers to have answers for their questions. As Saunders beautifully explains:

We fail to understand what patients really expect of us. They are commonly too realistic to expect that we can take away the whole hard thing that is happening, but they do ask for concern and care for the distress and symptoms it is causing them. Above all, they ask for our awareness of them as people.⁶⁴

Being present for others is a privilege bestowed on those who choose to care for others in their entirety. Being able to alleviate pain and suffering by providing symptom control measures whilst acknowledging the emotional distress that many times accompanies the physical pain, gives the understanding of care ethics a human dimension. Since a person and the experience of an illness are not only made up of a physical dimension but of the emotional too, recognising emotions as an important aspect of moral deliberation remains paramount.

Emotions are described in a myriad of different ways and are many a time considered irrational, which may thus ascribe to a real or perceived clouding of moral judgements. Ethics of care, on the other hand, values emotions as relevant to ethical reasoning. Also, care ethics acknowledges that although emotions may be subjective in nature, this does not automatically equate as to be irrelevant. Emotions elevate caring

⁶⁴ Saunders, "Care of the Terminal," 162-163.

beyond being merely a job that needs to be done. Acknowledging emotions means acknowledging our interdependency, which if fully embraced, would mean that society at large recognises that care can be both a personal and a public value.

2.3 Care as a Personal and Public Value

In the introduction of the book *Caring Democracy: Markets, Equality, and Justice*,

Tronto writes:

Let's face it: care no longer seems to be "at home," neither literally nor figuratively. It used to be so simple. Politics was something that happened in public, care was something that happened in private. Many societies followed one or another form of this public/private divide.⁶⁵

This statement suggests that since the public and private spheres were considered as divided and thus not interrelated, members of any given society had their own specific or society-assigned role(s) to effectuate. Considering the arguments and debates related to politics and care that have been ongoing for centuries, it becomes clear that this divide may have multiple implications which may also not bode well on the overall wellbeing of individuals and societies.

Since issues pertaining to the private and the public as understood in ethical theories are vast, this section will focus on three specific aspects. Although by no means in an exhaustive manner: gendered care, the distinction between the personal and the public, and a caring society, which are deemed to be relevant to the process of dying at home, will be discussed herein.

⁶⁵ Joan C. Tronto, *Caring Democracy: Markets, Equality, and Justice* (New York: New York University Press, 2013), 1.

2.3.1 Gendered Care

Considering politics as being public and care as being private, is suggestive of a gendered notion, which notion is described as being “connected either overtly or covertly, either explicitly or metaphorically with gender or sexual difference.”⁶⁶ This divide stems from the fact that politics were considered as the exclusive dominion of males, whilst care was *expected* to be carried out by females. This has created a problematic and even unethical situations, by which females were considered as inferior to their counterparts as they were expected to ‘serve’ and be submissive to their fathers and husbands. However, although the state of affairs just described was, and at times remains a reality, they are also depictive of the male as always being an uncaring being.

To this end, Tronto asks an important question, “do men care?”⁶⁷ She answers in the affirmative and suggests varying instances with which her claim is supported. Tronto indicates for example, that men do care: for themselves, for their children, and their elderly parents.⁶⁸ Hospice palliative care is a good example of the capabilities of men to care. Firstly, the hospice team, similar to teams in other healthcare settings, is made up of health professionals of both genders. Secondly, in the home setting, it is a common occurrence that a husband, son, brother, or a nephew will be the primary carer of a dying person.

Despite the caring disposition with which men are endowed, the idea that they are not able to care persists, probably influenced by factors such as societal values, class,

⁶⁶ Charlotte Witt and Lisa Shapiro, “Feminist History of Philosophy,” The Stanford Encyclopedia of Philosophy (2021), accessed November 21, 2021.
<https://plato.stanford.edu/archives/sum2021/entries/feminism-femhist/>.

⁶⁷ Tronto, *Caring Democracy*, 68.

⁶⁸ *Ibid.*

religion, and ethnicity amongst other possibilities. It is thus argued that if this idea remains unchallenged, then “there is *no hope* that our society can rethink caring responsibilities to become *more caring or more democratic*.”⁶⁹ This is indeed quite a heavy statement which requires to be seriously pondered by various stakeholders including individual persons, societies at large, governments, and law makers who should strive to ensure that care tops the hierarchy of any given society’s concerns.

2.3.2 Distinguishing Between the Private and the Public

From its inception, care ethics has sought to emphasise that care and caring are, and should, be embraced as universal values by all human beings, in all domains. Held posits that care ethics “reconceptualizes traditional notions about the public and private.”⁷⁰ Consequently, considering care both a private and a public value became one of the cornerstones of care ethics. However, this stance was oftentimes rejected or contested since it was not clearly understood how care, which is considered an intimate activity, can be incorporated into the public domain.

Kittay proposed what seems to be a simple explanation of how this merging could be achieved. She states that “the virtues that guide care in intimate spheres can introduce new values into the public domain.”⁷¹ Held cogently explains some of which may be considered as positive implications, if values pertaining to the private domain could be broadened to the public:

Persons will be valued for their own sakes as distinct, particular persons rather than as instances of abstract rational beings; relations of caring between persons will be morally evaluated and where appropriate cultivated as valuable; and close attention and responsiveness to persons’ needs will be part of the caring relations being cultivated.⁷²

⁶⁹ *Ibid.*, 67-68 (emphases added).

⁷⁰ Held, *The Ethics of Care*, 12.

⁷¹ Kittay, “The Ethics of Care,” 56.

⁷² Held, *The Ethics of Care*, 130.

Hence, considering care as a public value may effectively be easier to comprehend and to accept since it mainly revolves around the value that is placed onto a person, the relationships fostered between persons, and attentiveness to the needs of others. This description resonates care ethics and thus it may be the reason why Held advocates care ethics as the most appropriate theory to handle issues pertaining to societies.⁷³

The meaning of care in the private and public spheres differ for a myriad of reasons, amongst which; the place of care, the care provider, and issues of politics, justice, fair distribution, and equity. This requires an understanding of what pertains to the private and what is considered as public. Bowden, for example, classifies mothering, friendship, and nursing as pertaining to the private, whilst attributing citizenship to the public sphere.⁷⁴ She considers these three caring verbs as happening in a familiar environment and which seek to foster “caring relations between persons.”⁷⁵

Citizenship, on the other hand, is considered as being “ruled by thought, universality, objectivity, and the ability to act on abstract principles.”⁷⁶ In simpler terms, it is care which happens in broader societies and which thus, may tend to favour more a theory of justice first described by political philosopher John Rawls. Although the mode of moral reasoning between justice and care differs, political philosophy professor Daniel Engster argues that it is possible that caring can be expressed as a sort of justice

⁷³ *Ibid.*, 131

⁷⁴ Bowden, *Caring. Gender-Sensitive Ethics*, 141.

⁷⁵ *Ibid.*

⁷⁶ Evelyn Nakano Glenn, “Creating a Caring Society,” *Contemporary Sociology* 29, no. 1 (2000): 85.

theory.⁷⁷ However, he further specifies that it should be “a justice theory that designates caring for others in a caring manner as the most fundamental human value.”⁷⁸

The incorporation of the term ‘fundamental human value’ essentially poses a responsibility on all human beings. This is because all humans will at some point in their lifetime be part of some form of relation in which one hopes that one is valued as an individual and an unrepeatable being. Children rely on their parents, elderly parents on their children, patients on healthcare workers, citizens on their government, and so on. Collectively, these different relations in which some sort of care and caring is involved, make up the society of whom one makes part. Akin to this, Held explains that:

Caring relations, rather than what persons do as individuals, exemplify the values of caring. The small societies of family and friendship embedded in larger societies are formed by caring relations. More attenuated but still evident caring relations between more distant people enable them to trust each other enough to form a social organization and political entities and to accept each other as fellow citizens of states.⁷⁹

In essence, Held manages to illustrate how the personal and public should not be considered as exclusive spheres but as interrelated, since the caring relations in the private sphere(s) will eventually permeate the public. This can then hopefully facilitate the fostering of a society that values care and caring.

2.3.3 A Caring Society

The fostering of a caring society is considered as desirable and has several implications which, nonetheless, are not all positive. A question which remains moot, is *why* we should care for those outside our family/friendship circle. The answer to this question is varied since care may be considered in a multitude of ways amongst which:

⁷⁷ Daniel Engster, “Rethinking Care Theory: The Practice of Caring and the Obligation to Care,” *Hypatia* 20, no. 3 (2005): 70.

⁷⁸ *Ibid.*

⁷⁹ Held, *The Ethics of Care*, 168.

a value, a moral obligation, and a duty. In fact, Engster remarks that “it is important to develop a theory of moral obligation explaining why we should care for others and for whom exactly we ought to care.”⁸⁰ A caring society will have to recognise and accept dependency on each other as congruent to care. This remains an area of contestation and resistance, since being able to admit that we may need others, requires acknowledging our vulnerability.

Kittay states that “when we acknowledge how dependence on another saves us from isolation and provides the connections to another that makes life worthwhile, we can start the process of embracing needed dependencies.”⁸¹ With this statement, Kittay manages to provide an alternative way of understanding and of conceptualising dependency on each other. She brings to the fore the issue of isolation which is a common reality especially during a period of illness, and also during a dying process. A way of avoiding isolation and reinforcing the value of dependency may come from the role of the community itself.

Community care, to a certain extent, can take onto itself some of the responsibilities which are no longer able to be carried out by a sick person.⁸² The word ‘community’ can be considered as nuanced since it is subject for various interpretations. Dugdale states that there are three levels of community with family and friends considered as the foundation of every community.⁸³ She also describes the “*societal community*,” as those who provide some sort of service to support the elderly⁸⁴ such as

⁸⁰ Engster, “Rethinking Care Theory,” 57.

⁸¹ Kittay, “The Ethics of Care,” 57

⁸² Alcott Ridenour and Sowle Cahill, “The Role of the Community,” (see chapter.1, n.64): 121.

⁸³ Dugdale, *Lost Art of Dying* (see Introduction, n.2), 61.

⁸⁴ *Ibid.*

home-help. Lastly, she describes a “*biomedical community*,” which include the “healthcare professionals who accompany particular patients as illness takes hold and death draws near.”⁸⁵ In the care of the dying at home, the role of hospice palliative care is congruent to the description of the biomedical community care. Together with the family, at times friends and neighbours, and other services both from the public and private sectors, Hospice strives to care for the dying at one’s own home which is considered as requiring both a relational and communal dimension.⁸⁶ Collectively, caring for the dying at home encompasses all three community levels as described by Dugdale.

Perhaps, as Tronto suggests, “the unwillingness to recognize the role of care in our lives probably stems from our incapacity to comprehend death.”⁸⁷ If this is the case, then individual selves and societies at large are bound to lose. Since death will inevitably happen, the opportunity to foster caring relationships both in the personal and public domains will be lost to the vain attempt to conquer death itself.

2.4 Conclusion

Caring for the dying at home differs from the hospital setting for a myriad of reasons and which, consequently, is subject to different moral dilemmas too. Hence, this chapter has sought to provide an understanding of which, out of all possible ethical theories, would best suit the practice of dying at home. It was argued that care ethics is the most appropriate one, mainly in view of the features to which it ascribes. Thus, three major features of care ethics; responding and attending to the needs of others, the value of emotions, and care as a private and public value, as described by Virginia Held were

⁸⁵ *Ibid.*, 62.

⁸⁶ Ridenour and Cahill, “The Role of the Community,” 21.

⁸⁷ Tronto, “An Ethic of Care,” 19.

individually considered and discussed. Collectively, they provide a sound framework by which moral dilemmas pertaining to caring for the dying at home can be understood, deliberated, and acted upon. This is because care ethics focuses on the value of the person as an individual but simultaneously appreciates interdependency, takes into consideration the emotions all too common in the dying process, and also endorses care both as a personal and as a public value. Hospice palliative care also embraces these features, thus, inadvertently, it supports a care ethics framework both as a philosophy and through its *modus operandi*. However, although discussing care ethics within hospice palliative care is important, it becomes futile if ultimately the service does not reach those who would benefit from it. Therefore, the next chapter will be discussing the changes that are deemed to be required to further enhance hospice palliative care.

Chapter Three: Towards Change

It has been well established that caring for the dying and the death process *per se*, are at times considered as inadequate, inappropriate, and an experience which verges onto the undignified. The reasons for this state of affairs include, but are not limited to those which have been described in chapter 1, which mainly revolve around what was described as a medicalised death. A much too common question on how this situation should be addressed remains. In chapter 2, it was suggested that considering the attributes of a care ethics framework in the care of the dying, might indeed be the point of departure to mitigate this situation. Also, since it was established that hospice palliative care embraces an ethics of care philosophy, considering care ethics for the moral deliberation in caring for the dying in a home setting, may contribute to a more dignified dying process.

The gap between theory and practice, described as “a space between where we are and where we want to be,”¹ however remains. Thus, their bridging requires serious deliberation, a will to act, and tangible action(s). A relatively ‘young’ speciality, hospice palliative care has diffused in nearly all countries worldwide and has also been recognised as an important chain in healthcare systems. However, accessibility to those who would benefit from such care remains problematic for a variety of reasons. Considering that “over half of all deaths happen without palliative care or pain relief,”²

¹ Thomas, *Caring for the Dying* (see Introduction, n. 3), 4.

² Michael Cook, “Towards a New Vision for Death and Dying,” accessed February 26, 2022, <https://bioedge.org/end-of-life-issues/towards-a-new-vision-for-death-and-dying/>.

and that “health and social inequalities persist in death,”³ should prompt today’s societies to act in mitigating these situations.

This chapter will hence discuss the need for a cultural change as a means of counteracting the issues discussed in chapter 1 and also as the reaffirmation of hospice palliative care as a form of care ethics as described in chapter 2. It will be divided into three sections. In section one, the need to broaden the understanding of hospice palliative care both on a local and global level will be addressed. The second section will discuss the course of action needed to increase the public dimension of care, including financial considerations. Finally, section three, will be devoted to the understanding of the art of dying well.

3.1 Broadening the Understanding of Hospice Palliative Care

Perhaps the main point of contestation and which thus may affect the understanding of what hospice palliative care stands for, is attributed to the several nuances of the meaning of hospice palliative care itself. Although Saunders’ idea of the modern Hospice was inspired by her sound religious belief,⁴ it embraced people of different creed, culture, social status, age, and ethnicity. The term palliative⁵ care was later coined by Balfour Mount, an American oncologist who felt that the philosophy of hospice care could be amalgamated with the care offered in the “high-technology

³ *Ibid.*

⁴ Joy Buck, “From Rites to Rights of Passage: Ideals, Politics, and the Evolution of the American Hospice Movement,” 19, in *Hospice Ethics: Policy and Practice* (see chap.2, n. 8).

⁵ Palliative stems from the Latin word *palliare*, which roughly translates to ‘to cloak,’ ‘to protect.’ Palliative care aims to control the symptoms which may accompany a chronic, life-limiting, or malignant disease.

environment of the modern hospital.”⁶ Thus, through Mount, the concept of hospital-based palliative model of care, was established.⁷

Even though at its inception hospice palliative care catered for cancer patients, it evolved to embrace other serious and life-limiting conditions such as Motor Neurone Disease (MND), Multiple Sclerosis (MS), dementia, and end-stage cardiac, respiratory, liver, and renal disease. However, this list is not exhaustive since the inclusion criteria differs between countries.

Locally, Hospice Malta, which is a non-government organisation, founded in 1989,⁸ provides free of charge palliative care to cancer, MND, and end-stage cardiac, respiratory, liver, and renal disease patients. As of March 2022, Multiple Sclerosis (MS) and Creutzfeldt-Jakob Disease (CJD) have been included too. At the time of writing, hospice services are solely community-based. The building which will host St. Michael Hospice,⁹ which will eventually cater for all current services and which will also include in-patient services, is undergoing major refurbishment.

Presently, in-patient palliative care is provided at the palliative care unit located at Sir Anthony Mamo Oncology Centre. The 16-bedded unit is the only palliative care unit available, and to date, only one palliative consultant is engaged to cater for the whole population of the Maltese Islands. Also, the palliative team, caters exclusively for cancer patients. Thus, persons requiring palliative care for other conditions as described above,

⁶ Kenneth J. Doka, “Historical and Contemporary Perspectives on Dying,” in *Handbook of Thanatology: The Essential Body of Knowledge for the Study of Death, Dying, and Bereavement*, ed, David Balk (Kentucky: Routledge, 2007), 21.

⁷ *Ibid.*

⁸ Hospice Malta, accessed January 13, 2022, <https://hospicemalta.org/>.

⁹ St. Michael Hospice, accessed January 13,2022, <https://hospicemalta.org/st-michael-hospice/>.

are not referred to palliative care and are admitted to general wards at Mater Dei and Gozo General Hospital whenever they require in-patient care.

3.1.1 Goals of Care

Hospice care and palliative care share similar goals of symptom control, pain relief, patient comfort, and a focus on quality of life, whether a patient is facing a life-limiting diagnosis, a serious chronic disease, or has reached the dying phase. Palliative care can be provided in tandem with oncology treatment, mostly in symptom control, psychological support, and the nurturing of hope for a better quality of life through the treatment process.¹⁰ Hospice care focuses on symptom control and on a good quality of life in situations where a cure is no longer possible or the person opts to forgo curative treatment. Hospice care is concerned not only with the patient but also with significant others since it is understood that the end of life experience can be overwhelming for all those involved in the care of the dying. It is established that hospice care is always palliative in nature, but not all palliative care is hospice care.¹¹

Over the years, several definitions of Hospice, palliative care, and hospice palliative care were offered. For example, the American Cancer Society defines hospice care as:

A special kind of care that focuses on the *quality of life* for people and *their caregivers* who are experiencing an advanced, *life-limiting illness*. Hospice care provides compassionate care for people in the last phases of incurable disease so that they may live as fully and comfortably as possible.¹²

In contrast, palliative care is defined by the World Health Organization as:

An approach that improves the *quality of life* of patients (adults and children) *and their families* who are facing problems associated with *life-threatening illness*. It prevents and

¹⁰ Stein Kaasa *et al.*, "Integration of Oncology and Palliative Care: A Lancet Oncology Commission," *Lancet Oncology* (2018): e637, accessed December 5, 2021, www.thelancet.com/oncology.

¹¹ Stephen R. Connor, "The Family, Larger Systems, and Dying," in *Handbook of Thanatology*, 38.

¹² "What is Hospice Care?" American Cancer Society, accessed December 6, 2021, <https://www.cancer.org/treatment/end-of-life-care/hospice-care/what-is-hospice-care.html>, (emphases added).

relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.¹³

For Hospice Halifax, hospice palliative care “means providing opportunities for patients and families to uniquely address practical, physical, emotional, and spiritual needs while preparing for the patient’s death.”¹⁴

The similarities between these three definitions is evident and thus, this may explain why the terms are confused, used interchangeably, and at times feared too. Fear is mostly related to the loss of hope for a cure and the uncertainty of what is to come. This fear might also stem from the fact that palliative care and so also hospice care, maybe considered as the “continuation of the long struggle to accept life on its own terms, honestly and openly.”¹⁵ In simpler terms, the mentioning of hospice palliative care may instil a sense of foreboding which may be related to the fact that death, as a subject and a reality, is mostly shunned as was discussed in chapter 1.

It is thus quite a common occurrence that terms such as ‘comfort care’ and ‘support care’ are used as an alternative to hospice and palliative care, generally in an attempt to hide the diagnosis and prognosis from a patient. This is especially real in instances wherein the truth was withheld from the patient at the diagnosis of a disease with the false belief that the patient is ‘protected.’ Ariès describes this situation as ‘the lie’¹⁶ by which ultimately the patient will not benefit. However, even if a person is told the diagnosis, one might still ‘deny’ the reality. At times the denying of a prognosis is a

¹³ “Palliative Care,” World Health Organization, accessed December 6, 2021, <https://www.who.int/news-room/fact-sheets/detail/palliative-care>, (emphases added).

¹⁴ “Hospice Palliative Care: A Definition,” Hospice Halifax, accessed January 22, 2022, <https://hospicehalifax.ca/hospice-palliative-care-a-definition/>.

¹⁵ Matthew J. Loscalzo, “Palliative Care: An Historical Perspective,” *Hematology. American Society of Hematology Education Program* 1 (2008): 465, doi: <https://doi.org/10.1182/ASHEDUCATION-2008.1.465>.

¹⁶ Zimmermann and Rodin, “The Denial of Death Thesis,” 122 (see chap.1, no.32).

“psychological coping mechanism”¹⁷ for a person as a way to deal with such a life-changing reality and as a means of preserving hope,¹⁸ and hence should be respected.

It has been well established that patients would want to know their diagnosis¹⁹ and that “patients in fact want to know that they are dying but are denied access to this information by the rest of society.”²⁰ This denied information may translate into several repercussions. For example, the patient is stripped of the right to choose the appropriate care and services which best suit his or her needs. Thus, the goals of care, which may revolve around comfort and quality of life up to the end, risk to be jeopardised.

On a local level, it has been established that there is a “need to adequately inform patients about their diagnosis (and possibly their prognosis) and also the need to discuss the preferred place of care of people. The latter is quite novel for Malta.”²¹ The preferred place of care does not necessarily mean as being the same as the place of death. However, having an idea of the patient’s wishes earlier on may facilitate the planning and provision of care to be delivered.

In order to try to transform the idea of hospice palliative care from a taboo to a norm, it is suggested that we should start thinking in terms of ‘palliative culture’²² rather than of palliative care. It is also argued that should palliative care be introduced “in the curative phase of treatment helps with building a therapeutic alliance, and eases the

¹⁷ Ezekiel J. Emanuel and Linda L. Emanuel, “The Promise of a Good Death,” *The Lancet* 351, (1998): 25.

¹⁸ *Ibid.*

¹⁹ See for example, Joelle Azzopardi *et al.*, “Breaking Bad News in Cancer: An Assessment of Maltese Patients’ Preferences,” *Malta Medical School Gazette* 1, no.4 (2017): 36-45.

²⁰ Zimmermann and Rodin, “The Denial of Death Thesis,” 123.

²¹ Jürgen Abela, “Practical Aspects of Palliative Care,” *The Journal of the Malta College of Family Doctors* 2, no. 2 (2013): 18-19.

²² Julie Blanchard, “Resisting,” 90, in *Euthanasia: Searching for the Full Story*, (see chap.2, n. 58).

transition into palliative care when curative care is no longer an option.”²³ This would therefore facilitate the acceptance that the disease has reached the point where curative measures need to make way to comfort and symptom control.

Oncologist Benoit Beuselinck notes that “the purpose of palliative care can be summed up in two Latin words: *‘consolare et sedare,’* to bring comfort and peace – a peace which is physical, as well as psychological, spiritual, and social.”²⁴ Hospice palliative care should therefore be considered and accepted as a norm rather than an exception since its main focus remains the comfort of a person, and also because its need is ever on the increase.

3.1.2 The Need for Hospice Palliative Care

Even though hospice palliative care has established itself as an important speciality in the medical field, at times it remains at the fringes of the healthcare system. Many a time it is considered as a last resort when a patient’s health status is dire, where no other ‘options’ are viable, and where hope is beyond reach. This understanding may be a cause for late referrals, and where focus is placed on the negative aspects of a terminal diagnosis rather than on the positive aspects that hospice care can deliver.²⁵ However, it is an indisputable fact that its need is on the rise since as a result of advances in medicine, people afflicted with a life-limiting disease are living longer and thus, “we have a moral obligation to increase the quality of life of those prolonged lives.”²⁶ Also,

²³ Blanchard, “Resisting,” 90.

²⁴ Benoit Beuselinck, “The Meaning of Suffering or the Meaning of Life Despite Suffering,” in *Euthanasia: Searching for the Full Story*, 84.

²⁵ Bruce Jennings, True Ryndes, Carol D’Onofrio, and Mary Ann Baily, “What is Hospice Care?” in *Access to Hospice Care: Expanding Boundaries, Overcoming Barriers*, Hastings Centre Report Special Supplement 33, no. 2 (2003): S9, accessed May 25, 2021, <https://www.thehastingscenter.org/publications-resources/special-reports-2/access-to-hospice-care-expanding-boundaries-overcoming-barriers/>.

²⁶ Zimmermann and Rodin, “The Denial of Death Thesis,” 127.

advances in cancer treatment has made it possible for people to live with a metastatic disease for longer, a situation which has “reshaped cancer into a chronic illness,”²⁷ and hence, an increased need for hospice palliative services.

Unforeseen, devastating circumstances like the current SARS-CoV-2 (COVID-19) pandemic further reinforced the urgency that hospice palliative care is to be given the recognition it deserves. However, it has also brought to the fore several deficiencies in the present healthcare systems,²⁸ which thus need to be addressed in order to be able cater for the ever-increasing demand. It is estimated that in 2020, in the United Kingdom, the need for home palliative care reached a level which was expected to be reached by 2040.²⁹ Several factors were attributed to the surge in referrals to home palliative care amongst which the need to free up beds in hospitals, the choice to remain at home to avoid being isolated from family members, the non-visiting policies which were being imposed in almost all healthcare settings, and the fear of becoming infected whilst being in-patient.³⁰

Locally, referrals to Hospice Malta in 2020 slightly decreased over 2019. In 2019, 720 people were referred whilst in 2020, the number stood at 689.³¹ However, this number increased to 749 in 2021.³² It is interesting to note that although the number of referrals was lowest in 2020, the number of home deaths of those receiving home

²⁷ Kaasa *et al.*, “Integration of Oncology and Palliative Care,” e591.

²⁸ Cicely Saunders International, “You Matter Because You Are: An Action Plan for Better Palliative Care,” (2021), 2, accessed December 5, 2021, <https://cicelysaundersinternational.org/action-plan-for-palliative-care/>.

²⁹ Irene J. Higgins, David Brooks, and Stephen Barclay, “Dying at Home During the Pandemic,” *BMJ* 373, no. 1437 (2021): 1, doi: <http://dx.doi.org/10.1136/bmj.n1437>.

³⁰ *Ibid.*

³¹ Anna Frendo, e-mail message to author, January 17, 2022.

³² *Ibid.*

hospice care was the highest at 145.³³ In 2019, the number of people who died at home was 78 whilst in 2021 it was 140.³⁴ It needs to be established whether the rise in demand for hospice palliative care was due to the satisfaction with the services it provides, or else because no other viable option was available.

On the other hand, a worrying observation is that globally, people who required access to palliative care during the pandemic were unable to do so.³⁵ The reasons for this are varied but are mostly believed to be attributed to the overwhelming demand for the service, understaffing of professionals, and measures to avoid contagion - mainly, the decrease in face-to-face interaction with healthcare professionals.

The effects of the COVID-19 pandemic on hospice palliative care will last well after it is declared that 'it is over.' This is in view of the possible long-term health ramifications COVID-19 can have on those who were severely affected, and who would thus require hospice palliative care in the near future. Locally, Hospice is presently providing its services to five post-COVID-19 patients;³⁶ the number is envisaged to rise in the coming months and years.³⁷ Also, a few months into the pandemic, Hospice Malta recognised the need to extend its bereavement support services to the families of COVID-19 victims,³⁸ a proof that Hospice can be pro-active in the face of adversity. To date, this service is still ongoing.

³³ *Ibid.*

³⁴ *Ibid.*

³⁵ Cicely Saunders International, "You Matter Because You Are."

³⁶ Anna Frendo, e-mail message to author, January 17, 2022.

³⁷ *Ibid.*

³⁸ See, Fiona Galea Debono, "Families of COVID-19 Victims Offered Bereavement Help," *Times of Malta*, October 2, 2020. <https://timesofmalta.com/articles/view/families-of-covid-19-victims-offered-bereavement-help.821629>.

As the Director General, World Health Organization, Tedros Adhanom Ghebreyesus, aptly remarks:

The COVID-19 pandemic has highlighted the importance of palliative care in all health care systems. The need for relief from severe suffering, the difficult decision making, and complicated grief brought on by the pandemic are exactly the types of problems that palliative care was designed to help address. The world will be a better place when palliative care is available to all who need it.³⁹

Reflecting on this statement, one can conclude that beyond a cure, healthcare in general should strive to focus more on the relief of suffering in all its forms; physical, emotional, psychological, and spiritual. The multifaceted challenges of an illness as highlighted by Ghebreyesus require that more consideration is given to all of these challenges, which should also include an increased effort to provide access to hospice palliative care in an equitable and timely manner.

3.1.3 Access to Care

Access to quality hospice palliative care should not be different to that of other health care services. Caring for the dying should not translate into a shoddier quality of care and services simply because the person 'is dying.' Palliative care is a human right and "under international law, there are two main sources for this right: the right to health and the right to be free from cruel, inhuman and degrading treatment."⁴⁰ This poses serious responsibility on individual governments, policy makers, legislators, health care providers, and the international community.

Access to care is multifaceted as it is made up of a combination of aspects, the most basic remains the availability of the service in a particular country in the first place. In

³⁹ Tedros Adhanom Ghebreyesus, "Forward," in *Global Atlas of Palliative Care*, 2nd edition (2020), 10, accessed January 13, 2022, <http://www.thewhpca.org/>.

⁴⁰ Stephen Connor, Claire Morris, and Frank Brennen, "Introduction," in *Global Atlas of Palliative Care*, 15.

Malta, healthcare services are funded through social security contributions and taxation, similar to England's National Health Service. Access to palliative and hospice care is therefore available to all those who require their services. However, in some instances, some individuals may be required to pay for the services provided by the government. In the case of Hospice, the service remains free of charge for all who require it irrespective of whether social contributions are paid or not.

It has been well established that differences between low, middle, and higher income countries play a major role in accessibility to care. It estimated that only 12% of the global palliative care needs are being met.⁴¹ This estimate is extremely worrying, since each number in a statistic represents a person. Denied or non-existent access to care translates into suffering for the afflicted person.

Another worrying reality is the inaccessibility of the provision of pain relief measures, mostly opioids. In fact, it is estimated that around 83% of the countries worldwide have low or even non-existent access to opioids for pain relief.⁴² This situation may be considered as a form of an injustice, congruent to a violation of human rights. Also, since "effective symptom relief is the primary clinical emphasis for hospice clinical care givers,"⁴³ inadequate access to pain relief may negatively impact the delivery of hospice palliative care.

Understanding hospice palliative care and what it stands for is imperative. However, several other challenges beyond an understanding need to be considered if

⁴¹ Ghebreyesus, "Forward," 10.

⁴² James Cleary *et al.*, "What are the Main Barriers to Palliative Care Development?" in *Global Atlas of Palliative Care*, 34.

⁴³ B. Andrew Lustig, "Death, Dying, Euthanasia, and Palliative Care: Perspectives from Philosophy of Medicine and Ethics," in *Handbook of Bioethics: Tacking Stock of the Field from a Philosophical Perspective*, ed. G. Khushf (Dordrecht: Kluwer Academic Publishers, 2004), 460.

the goal of it reaching more people is to be achieved. This will be discussed in the following section.

3.2 Increasing the Public Dimension of Care Including Financial Considerations

Considering care as both a private and a public value was discussed in chapter 2. However, in order to move beyond the consideration and perhaps acceptance of care as a public value, the need to increase the public dimension of care will be addressed in the first part of this section. Financial considerations, which remain an important and challenging aspect for the provision of care, will be discussed in the second part of this section.

3.2.1 Public Dimensions of Care

Professor John M. Stanley asks;

If hospice-type end of life care is thought to be so good and so helpful by such a high percentage of both patients and families experiencing it, why don't more dying people make use of it and why don't those who use it do so sooner?⁴⁴

Attempting to answer these legitimate questions might give us a better understanding of what might be hindering people to reach out to hospice palliative care when required. There might be several reasons for this situation which ultimately might be somewhat all related to a deficiency in the dissemination of information on the service. In order to avail oneself of a service, one must be aware that it exists, know who the potential beneficiaries are, what are its benefits, payment requirements, how to access the service, and other relevant information. However, information may be less forthcoming even from healthcare professionals themselves perhaps because people feel

⁴⁴ John M. Stanley, "What People Would Want if They Knew More About it: a Case for the Social Marketing of Hospice Care," in *Access to Hospice Care*, S22.

uncomfortable acknowledging finitude, and a referral to hospice palliative care will bring this reality to the fore.

End of life care, an integral aspect of hospice care, has “long been considered a societal problem that needs to be improved,”⁴⁵ and which meets “the criteria of a public health priority.”⁴⁶ These statements carry a considerable weight since public health is usually broadly equated to health promotion, prevention of disease, and public awareness. At face value, caring for the dying does not fit into this description. However, end of life care goes far deeper than tending for ‘a dying body.’ It is caring for a dying person who has reached the twilight of his or her life, who thus might be experiencing symptoms to be controlled, pain to be resolved, and emotions which need to be addressed. It is asserting that a good quality of life, so revered in public health policies, needs to be upheld till the very end.

Increasing the public dimensions of hospice palliative care therefore requires that people are informed about its existence, eligibility, access, and the services it provides. This thus requires that professionals discuss end of life issues and care more frankly with their patients. However, as Kübler Ross observes, “we have to take a good hard look at our own attitude toward death and dying before we can sit quietly and without anxiety next to a terminally ill patient.”⁴⁷ In reality, discussing death and dying is never easy, even with patients who are ready to do so. Still, this should not justify the unwillingness to learn how to speak about death and dying and how to listen to people. On the other hand, it also requires that people become more accepting of the reality of death and

⁴⁵ Jaya K. Rao, “Engaging Public Health in End-of-Life Issues: It Is Time to Step Up to the Plate,” *Annals of Internal Medicine* 162, no.3 (2015): 230.

⁴⁶ *Ibid.*

⁴⁷ Kübler Ross. *On Death and Dying* (see chap. 1, n.11), 255.

dying, not the romanticised type described in novels and operas where death is depicted as a *quasi*-perfect event, but death which unfortunately, sometimes, is painful, smelly, messy, but ultimately real.

3.2.2 Financial Considerations

Considering the financial aspects of caring for the dying, including in the home setting, is important since ultimately it might impact on the provision of and access to care. Thus, this section will consider Hospice's and the central government's financial investment in hospice palliative care as a kind of a community-based health service. It will also consider the financial burden families may experience; a situation which is quite too common and which merits a deeper understanding.

As with any other healthcare service provision, hospice palliative care is expensive. It requires a huge amount of investment both of monetary value and in terms of "training of staff, outreach and liaison to other providers serving seriously ill and dying patients, and development of policies and procedures."⁴⁸ Taking into consideration that locally, hospice is mostly funded through donations in conjunction with financial support from the central government, this is not an easy feat. For example, in 2020, Hospice Malta spent €1.3 million,⁴⁹ a figure which increased to €1.6 million in 2021,⁵⁰ in order to provide its community-based services. Government support was at the level of 44% of the cost in 2020 and of 62% in 2021.⁵¹

As discussed in chapter 1, caring for the dying at home is less expensive than in the hospital setting, since it does not make use of highly technological equipment, expensive

⁴⁸ Ratner and Song, "Ethics and Dying at Home," (see chap.2, n.4): 124.

⁴⁹ Kenneth Delia, e-mail message to author, December 12, 2021.

⁵⁰ *Ibid.*

⁵¹ *Ibid.*

drugs, intravenous infusions, endless investigations, and other possible services available in a hospital. However, this does not mean that home care is easy and straightforward. Time and again it has been argued that “caring for dying patients imposes significant economic demands and caregiving burdens on the family.”⁵² Hence, not all families will be able to care for a dying person at home even if the wish do so is there.

The economic demands on a family caring for a dying person can be enormous and multifaceted. Several factors such as; the age and social status of the patient himself or herself, if the patient is the main breadwinner, if he or she has lost their job, and if they are receiving some type of social benefits, need to be considered. Also, is the patient’s spouse or partner, if any, engaged in a paid job? Are they being allowed to take time off to tend for the sick person at home? If so, at what cost? Are there any young children who are fully dependent on their parents? Many a time, a social worker would be required to assess these situations, advise, and guide the family to the appropriate services in order to try to alleviate some of these concerns and burdens.

On the other end, one finds elderly couples with their own challenges. Some might think that because older patients may be pensioners, it will be easier for them to cope. This is a far cry from reality. An elderly person caring for a dying elderly spouse or relative faces hardship especially if the social support is lacking. The normal, age-related physical limitations of an elderly person are to be seriously considered in this particular situation. Also, many a time, an elderly person who is the main carer, might also be dealing with personal health issues which thus makes the task more difficult and complicated.

⁵² Emanuel and Emanuel, “The Promise of a Good Death,” 23.

The income of a family is a key issue in the scenarios just described, because a lower income may translate into less available resources.⁵³ For example, if a family needs to employ a carer to help caring for the dying person, or if specialised equipment needs to be hired, it would be hard to afford such services if the family's income is not consistent and considerable.

If one seriously considers the "recurring problems in community palliative care, such as lack of carer support or district nursing, or problems accessing drugs and equipment out of hours, etc,"⁵⁴ challenges all too familiar to the author of this study herself, it will become more clear why caring at home can be challenging. On the other hand, it is indeed disappointing that some people are not cared for and do not die at home as is their wish because "the necessary services are not there to support them,"⁵⁵ services which are expensive for any health care system, let alone for a family to fund them itself.

3.3 The Art of Dying Well

A 'good death', a 'peaceful death', and 'dying well' may be considered oxymoron phrases since attaching a positive adjective to a word which is considered negative, does not seem plausible. If dying well is considered as the continuation of living well, then it will be easier to comprehend how death can be described in a positive way. A main cornerstone of hospice palliative care is the understanding, facilitation, and support of a peaceful dying process of a person at one's home.

⁵³ Higgins *et al.*, "Do Social Factors Affect," 25.

⁵⁴ Thomas, *Caring for the Dying*, 5.

⁵⁵ Cicely Saunders International, "You Matter Because You Are," 5.

3.3.1 Dying Well

The idea of 'dying well' or a 'good death' is not recent but has its roots embedded in the medieval era, in the texts which described the practices of dying well - the *Ars moriendi* – the art of dying.⁵⁶

The *Ars moriendi* texts appeared in 1415⁵⁷ after the Black Death, which severely transformed the way caring for the dying happened before the plague. In pre-plague era, care of the dying used to take place in the home, with the family and the community being present and having defined and active roles. The *Ars moriendi* texts are believed to have been influenced by a previous text - *Scientia Mortis* – Knowledge of Death - written by the French theologian, Jean le Charlier de Gerson.⁵⁸ The *Ars moriendi* provided 'instructions' on how one is to prepare for death. Even though their origins were based on the Christian faith and thus it encouraged the dying person to reconcile with God, concomitantly, they offered a practical guide on how one is to care for a dying person. An interesting observation is that the texts also took into consideration the emotions a dying person was expected to face through the dying process.⁵⁹ Thus, it can be deduced that emotions as central to one's being as discussed in chapter 2, was already recognised in the 15th century.

It is argued that today's society should look retrospectively and evaluate how people used to deal with issues that are still present today. Presumably, dying remains the sole unchanged recurrent 'issue' for humans since the beginning of time. Despite the changes in its geography and rituals, the ultimate outcome - death - remained the

⁵⁶ Dugdale, *Lost Art of Dying*, 17.

⁵⁷ *Ibid.*, 34

⁵⁸ *Ibid.*, 33-34.

⁵⁹ *Ibid.*, 36.

same. To this end, Carlo Leget argues that “both society and medicine in general can benefit from a retrieval of this tradition by offering an active and positively oriented preparation for our common destiny as mortal creatures.”⁶⁰ Thus, what might be required is the appraisal and embracing of the rituals of our forefathers. Perhaps a good start would be the acceptance of the reality of death not only when it is evident that death is close, but also throughout the journey called life.

One of the instructions of the *Ars moriendi* specifically stated that “family and friends were to gather at the bedside and broach the uncomfortable subject of death; no one was allowed to offer false hope about recovery from illness.”⁶¹ This statement highlights two important issues that today’s ‘modern’ society grapples with. Firstly, the inclusion of family and friends emphasises the community’s approach to death; an aspect which is being lost by the segregation of the dying behind clinical doors and because “from a family event with occasional medical support,”⁶² death has been transformed into “a medical event with limited family support,”⁶³ as discussed in chapter 1. Secondly, false hope; a seemingly insurmountable issue which is being presented under the guise of cutting-edge medical technology and treatments. Similar to the *Ars moriendi*, Curlin argues that “for patients to engage in the task of dying well, it helps for them to know and to have those around affirm that they are dying, not merely sick,”⁶⁴ a difficult but necessary task with which the hospice team is frequently faced.

⁶⁰ Carlo Leget, “Retrieving the Ars Moriendi Tradition,” *Medicine, Health Care and Philosophy* 10 (2007): 319.

⁶¹ Dugdale, *Lost Art of Dying*, 36.

⁶² Cook, “Towards a New Vision.”

⁶³ *Ibid.*

⁶⁴ Farr A. Curlin, “Hospice and Palliative Medicine’s Attempt at an Art of Dying,” in *Dying in the Twenty-First Century* (see chapter.1, n.23), 51.

There exists a noticeable similarity between these aspects from the *Ars moriendi* texts and hospice palliative care philosophy. In fact, it is argued that in the way by which Hospice sought to transform the care for the dying, Hospice was attempting to revive the medieval practice of the *Ars moriendi*.⁶⁵ Hospice considers the active participation of a patient's family and at times, friends and even neighbours in the dying patient's care as paramount. As explained in chapter 2, Hospice advises, liaises with other community services and with the general practitioner, and provides practical and emotional support. Still, ultimately, the 'hands on' aspect(s) of care is carried out by the patient's family. However, "help from family members and informal carers is a critical and often overlooked component of care at home."⁶⁶ Thus, the family should be considered as an important link to the hospice team since it is generally acknowledged that a family's participation in care and the support it receives are amongst the main factors which determines if a patient dies at home or in the hospital.

3.3.2 Place of Death

There is *no universally right way* for a person to die. What constitutes dying well for one person might be entirely wrong for another. The word "well" is both an adverb and adjective. It can describe not only the dying process but, more important, the person who is dying.⁶⁷

In this statement, Byock highlights a very important observation. The phrase "no universally right way for a person to die," may at times be hard to understand. Since dying is the final phase of living and thus remains a personal issue, it may be influenced by social, cultural, and religious factors. The notion that the word 'well' can also describe a person is important as it reaffirms the belief - central to care ethics – that care should

⁶⁵ *Ibid.*, 47.

⁶⁶ Higgins, Brooks, and Barclay, "Dying at Home During the Pandemic," 1.

⁶⁷ Byock, *The Best Care Possible* (see chap.2, n.33), 81 (emphases added).

always revolve around a person's needs. Thus, this might reflect in a patient's preference for his or her place of care and of death.

The place where death takes place should not be equated to whether death was 'good' or 'bad.' Defining a 'good death' should consider other important aspects beyond a building. The interpretation of a 'good death' is considered as "broad and practical and enables us to understand that this is not simply a matter of how 'they' die but how deaths can be made as good as possible under today's cultural and social conditions,"⁶⁸ issues which were discussed in section 3.2.

Even though time and again it has been argued that people would want to die at home, this option although doable, is not always possible. Home as the most appropriate place of dying "vary according to individual, family, community, and cultural expectations."⁶⁹ Although hospice palliative care endorses and strives to make dying at home a possibility if this is the wish of the patient, it happens that this does not always materialise. One must not underestimate the fact that "for some death at home might be too tangible a reminder,"⁷⁰ of a painful experience and thus, dying at a hospital might be more appropriate. Dying in a hospital should not be considered as a sign of failure or worse a 'bad death' since "hospital deaths are inevitable for some and appropriate for others."⁷¹ However, what is required is enough support and coordination in community care as a means to avoid a 'crisis' admission to a hospital of a dying person being cared for at home. If we are really interested and committed to attempt to return the practice

⁶⁸ Liz Lloyd, "Mortality and Morality: Ageing and the Ethics of Care," *Ageing & Society* 24, no.2 (2004): 253.

⁶⁹ John Rosenberg, "Whose Business is Dying? Death, the Home and Palliative Care," *Cultural Studies Review* 17, no.1 (2011): 25.

⁷⁰ *Ibid.*, 26.

⁷¹ Thomas, *Caring for the Dying*, 18

of dying to the home setting, then, we need to strengthen the families' "ability to cope"⁷² in a crisis.

As Professor Keri Thomas aptly observes, "We all go this way once only. We have one chance to get it right – for ourselves and for our patients."⁷³ This poses a huge responsibility on all of us; the patient, the carers, the hospice team, and also the broader society. All should strive to embrace dying as the natural progression of life and thus facilitate a 'good death' wherever this may happen.

3.4 Conclusion

This chapter has sought to identify possible ways which may counteract the issues discussed in the previous two chapters. It was argued that hospice palliative care should be considered as a norm in the medical field and thus, people should become more aware of its existence and meaning. It was also argued that a way to normalise hospice palliative care is by its integration in the initial phases of a life-limiting diagnosis. However, this comes at a cost, and it was argued that the financial aspects should be seriously considered. This also applies to the financial burdens some families may face when they decide to take care of a dying person at home. Dying at home is a situation which many times is fraught with multiple challenges mostly due to a lack of support in terms of community care. Finally, the meaning of 'dying well' was sought. It was noted that this concept dates back to medieval times through the *Ars moriendi* texts. A parallel between the modern hospice palliative care philosophy and some aspects of the *Ars moriendi* were made. Thus, the notion that we can look retrospectively and transform 'old rituals' into contemporary practices in caring for the dying was reinforced. Also,

⁷² *Ibid.*,30

⁷³ Thomas, *Caring for the Dying*,16

although dying at home remains an important aspect of hospice palliative care, it was argued that defining a 'good death' should not be solely based on the place where death takes place, since the patient's preference, social situation, and support ultimately may dictate where death happens.

Conclusion

This work has sought to discuss some issues which are deemed responsible for the shift of dying at home - a practice which is central to hospice palliative care - to the hospital setting and the bioethical dilemmas this situation has brought with it. It was argued that the emergence and proliferation of medical technology has facilitated this shift. Several important changes in societal make-up have further contributed to this process. What was once considered a family and a community affair, dying, was being considered as an event which should happen out of sight and a subject which is not to be discussed.

Dying in a hospital setting gave way to new bioethical dilemmas in terms of access to care, justice, equity, and more recently the right to either futilely prolongate life or to end one's own life on request. These dilemmas are not alien to hospice palliative care since despite the best efforts in symptom control and the support for a good quality of life, at times hospice patients and also their relatives ask either for incessant treatment(s) or euthanasia even though they are aware that locally, euthanasia is not legalised as yet.

In order to try to circumvent these situations, and also as a means of trying to return death to the home setting, it was argued that we need to rethink hospice palliative care as a form of care ethics. Out of all possible ethical frameworks, care ethics was deemed to be most suitable in view of the particular features it endorses which mainly revolve around caring for a person both in the private and public spheres. Three particular aspects of care ethics as described by Virginia Held were discussed and a parallel between care ethics and hospice palliative care philosophy was drawn. Both care ethics

and hospice palliative care value the person in his or her totality, wherein attention is focused on every aspect which makes up a person including the much disputed emotions.

Hospice palliative care, as a health service, is inundated with ongoing challenges. These are mostly related to access to care, awareness, funding and sustainability, research, and the struggle to be recognised at par with other more established medical specialities. Thus, it is high time that the *status quo* in current practices is challenged.

i. Suggestions for Improvement

This work has brought to the fore several deficiencies in the provision of care for the dying which in turn might lead to the request for futile prolongation of life or on the other hand, the hastening of one's death. Thus, the following suggestions are being made in an attempt to improve the current situation. Any improvement is envisaged to benefit the patients, families, health care professionals, and society at large. The following suggestions are made in relation to the local situation.

1. Professional Development

Professionals, who in a way or another are bound to be in contact with people suffering a life-limiting or terminal disease, should be encouraged and offered opportunities to broaden their understanding on quality hospice palliative care. This should include appropriate communication skills in discussing end of life issues, death, and dying.

Locally, the European Certificate in Essential Palliative Care (ECEPC) is organised on a yearly basis by Hospice Malta in collaboration with University of Malta and Princess Alice Hospice, Esher. Application is open for all medical doctors and nurses who wish to

further their knowledge in palliative care. Nurses and doctors who are employed with Hospice Malta are expected to obtain this certificate in view of their direct work with hospice palliative patients. Medical doctors including general practitioners, and nurses from all healthcare areas would benefit from such courses since palliative care can be provided in different healthcare settings.

Since euthanasia may be bound to be discussed for possible inclusion in the Maltese legislation, hospice care team needs to be trained on how to discuss this issue with patients and their families. As the author has stated in chapter 1, she has already been faced with instances where a patient or a relative broached the subject of euthanasia. Knowing how to deal with such situations would benefit the patient and professional alike.

2. Research

Locally, research in the various facets of hospice palliative care is lacking. There is a great need to determine the strengths and weaknesses of hospice's services. Services can only be improved if deficiencies are identified, quantified, acknowledged, and ultimately addressed. Hospice's main resolution is to strengthen its present community services in conjunction with the opening of an in-patient unit in the near future. Thus, if Hospice is aiming to reach more people, then it should be in a position to plan for future demands. Research needs to include factors which might influence if a patient is cared for and dies at home. This is especially required since as discussed in chapter 3, statistics show that the number of hospice patients who died at home during the COVID-19 pandemic increased considerably. Thus, it needs to be established if this increase was due to the satisfaction with the services Hospice provides or by default.

The author acknowledges that research is not an easy endeavour for a NGO both on a logistical and monetary aspect; thus Hospice will require the backing and support of other organisations such as the health department and also private entities in order to do so.

3. Practices

Since Hospice collaborates with other healthcare entities, it can be influenced by practices and decisions of others. This is mainly felt in the cohort of patients who are cared for by the palliative team at Sir Anthony Mamo Oncology Centre (SAMOC) and those referred to Hospice. As explained in chapter 3, palliative care provided at SAMOC is solely cancer-based, whilst Hospice caters for other life-limiting illnesses besides cancer.

There is a need for the provision of palliative care through a designated team at both Mater Dei and Gozo General hospitals, in order to cater for non-cancer palliative patients who would require, benefit, and thus have a right for such care. This would also hopefully address the present anomaly in the Government Formulary List,⁷⁴ in which pain killers such as Morphine Sulphate® (in all forms), can only be prescribed in cases of malignancy and solely by a hospital consultant. Currently, non-cancer palliative patients cared for in the community who would require Morphine Sulphate® are not entitled to it, and a patient's general practitioner is not authorised to prescribe it.

There is a need for more synergy between the caring consultant, the discharge liaison nurses, Hospice, and community services as to avoid instances wherein a patient

⁷⁴ The Government Formulary List, accessed March 24, 2022, <https://deputyprimeminister.gov.mt/en/pharmaceutical/Pages/formulary/formulary.aspx>.

is discharged home without a proper discharge planning. Unfortunately, this is quite a common occurrence which leads to unnecessary suffering to the patient and his or her family and also to avoidable re-admissions.

Community services in general need to be strengthened with more services available for the longest hours possible. Presently, Hospice provides its services from Monday to Friday between 08:00 and 16:30 after which, an on-call service is available until 22:30. On-call service is also provided on weekends and public holidays between 08:30 and 22:30. The on-call service is provided by a nurse and is restricted to over-the-phone advice-giving to those who call. No visits are carried out during the on-call hours and the service is as yet not backed by a medical officer. This reinforces the need for the general practitioner's input which at times is also lacking.

Hospice's on-call service needs to be revised in conjunction with the provision of the in-patient palliative services in order to strengthen its already valuable function. The present structure of the community services provided by the health department also needs to be revised to better respond to contemporary needs of people being cared for at home. All community services provided by the central government, private entities and Hospice need to collaborate more to provide as seamless a service as possible to those who require it. Thus, a national palliative care strategy which addresses the identified and non-identified deficiencies in the present provision of palliative care is required.

Since as previously discussed hospice palliative care is inundated with ethical concerns, the need for a Hospice ethics committee is much overdue. This applies both to the present community-based services and more so, when St. Michael Hospice is up

and running. As previously accented to, the possibility of a national discussion to legalise euthanasia might bring new ethical challenges to Hospice's practices, and thus, it needs to be prepared in dealing with possible requests for euthanasia amidst other ethical concerns.

A serious consideration to provide a legal framework which recognises advance care directives is required. Presently, advance care directives are not legally recognised in Malta, thus patients are being stripped of their right to decide on their care which might include a timely referral to hospice palliative care.

ii. Limitations

Although great attention was taken to provide as high a level of work as possible, the author of this dissertation acknowledges several limitations of this study.

1. The subject of death and dying combined with hospice palliative care is vast and thus, several of the issues discussed which could have merited a deeper exploration, were only briefly explored. This includes the factors responsible for the shift of dying to the hospital, hospice palliative care philosophy, and the understanding of dying well.
2. The attempt to analyse a care ethics framework proved to be harder than anticipated and thus, the author may have not made due justice to the true nature of care ethics. This was mostly felt in 'care as a private and public value' which merited a more in-depth appraisal in view of its multifaceted aspects.
3. Even though great care was taken to avoid any biases, the author's professional role as a hospice nurse made this a more difficult task. Although unintentionally, some biases may be evident throughout the text.

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