

The body and its shadows: An exploration of the bodily experiences of terminally ill patients

Thesis presented for the Degree of Doctor of Philosophy

by

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Declaration of Authorship

I Ana Patrícia Hilário hereby declare that this thesis and the work presented in it is entirely my own. Where I have consulted the work of others, this is always clearly stated.

Signed: 

Date: September 2014

Abstract

To date, dying and its bodily realities have been a neglected issue within the sociological literature in Portugal and elsewhere. The present study intended to overcome this gap by exploring how and why the sense of self and identity of Portuguese terminally ill patients is affected by the process of bodily deterioration and decay. Thus it was grounded in the interpretative approaches of symbolic interactionism and social constructionism. The data was gathered by means of ethnographic research strategies. Participant observation was carried out in two Portuguese palliative care units and complemented by interviews. A total of ten terminally ill patients were interviewed, along with twenty family members and twenty palliative care professionals.

What was particularly revealing was that despite the detrimental impact that the process of bodily deterioration and decay had on a patient's sense of self and identity it did not lead to a debasement of their personhood. This was mainly due to the interpersonal interactions that took place within the palliative care context. The findings outlined suggested that palliative care provides a space for interaction where terminally ill patients could spend their last moments with their loved ones without being preoccupied by uncontrolled pain and symptoms, as well as without the concern of being a burden to them. The familistic nature of Portuguese culture informs the practice of palliative care in this country and thereby influences the processes of interactionality that took place within this environment. The study leads to the conclusion that in the face of dying and its bodily realities palliative care offers to terminally ill patients the opportunity to live fully until their death.

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Chapter One

Introduction

1.1. Introduction

This introduction aims to provide an overview of the current study. I will start by discussing the gaps within death and dying literature. I will then discuss the need to recognize diversity amongst the dying and the dying process and will underline the paucity of research relating to gender issues at end of life. Next I will outline the special case of Portuguese society. Attention will be paid then to palliative care in Portugal. The aims of the study will be briefly discussed. A short description of the theoretical framework adopted will be presented. Finally, the structure of the thesis will be outlined.

1.2. Filling the gaps in death and dying literature

Whilst there have been a number of studies in the domain of social sciences on death and dying which offered valuable insights into the provision of end of life care (Howarth, 2007; Kellehear, 2008; McNamara, 2001; Seale, 1998), little work has been done on the experience of in-patient hospice patients per se (Lawton, 2000; Broom and Cavenagh, 2011). This work has nevertheless constructed the hospice as a kind of liminal space or a non-space, which promotes a sense of dislocation and disintegration from the self. There has also been a tendency within social sciences literature to describe home as the preferred place for death and to downplay the importance of in-patient hospice care (Gomes et al., 2013b Higginson et al., 2013). The hospice might

nevertheless represent a meaningful and important space for negotiating end of life. Patients, for instance, might prefer to place their final care in the hands of professionals in a hospice as a way to maintain personal dignity and identity in the face of potential loss of bodily control. The preference for a hospice death in this sense lies in patients' wish to exercise agency (Thomas et al., 2004). The need to relieve the burden placed on the family might also influence patients' preference for a hospice death. This could be a way for patients to sustain their role as guardians of their family (ibid) and might be particularly true for Portuguese terminally ill patients. The familistic nature of Portuguese society could be extended to dying preferences. The well-being of family could in this light be seen as of paramount importance even in comparison to the prospect of one's impending potential death (Tavora, 2012).

This study is very timely as there has been a tendency by policy makers in recent years in Portugal to overemphasize the benefits of a home death (Capelas, 2010) by arguing that this is in accord with patients' preferences (Gomes et al., 2013b). While some advanced and seriously ill patients might prefer to die at home, there is a need for caution when analyzing home death policies. The need to increase the proportion of deaths at home might have less to do with matters concerning patients' choice and more with the need to reduce costs (Thomas et al., 2004). Thus, it seems to be an opportune time to conduct research on experiences of in-patient hospices in Portugal and to understand how the process of bodily deterioration and decay might shape and constrain this experience.

1.3. Who dies in the hospice?

It is necessary to recognise diversity amongst the dying and the dying process (Kellehear, 2009b). Within the literature on death and dying there has been a tendency to build 'its theoretical paradigms upon homogeneous categories such as the dying patient and the dying process' (Lawton, 2000: 145). Lawton's (2000) work with hospice patients can be seen as the first attempt to counter the 'reductionist and generalising tendencies of grand theorising' (Ellis, 2010: 5). Nevertheless, by focusing on the unbounded dying body Lawton presented a rather linear representation of the body during a hospice death (Broom and Cavenagh, 2010). According to Lawton the hospice is largely confined to patients with advanced cancer who suffer from different symptoms such as incontinence of urine and faeces, uncontrolled vomiting, fungating tumours and weeping limbs. Lawton indeed claimed that 'the hospice had become an enclave for some of the most distressing cancer deaths' (2000: 33). Whilst this may be so in some cases, I suggest that a more nuanced understanding of the hospice death is needed. The symptoms experienced by hospice patients might be highly differentiated (Broom and Cavenagh, 2010).

The situation in hospices might indeed be rather more complex than that described by Lawton. While the hospice might 'set the disintegrating body apart from mainstream society' (Lawton, 1998: 121), it might for example provide a space where the dying patient could exert a certain degree of control over the manifestations of their bodily disintegration (Broom and Cavenagh, 2010). Thus the intention of the current study is to offer a more comprehensive view of the dying process and its bodily realities. The term palliative care will be used instead of hospice as the latter is not a usual term in the

context studied. By recognising diversity among hospice deaths I hope to demonstrate that the intolerability of a ‘drawn out death’ might be related to the character of individual symptoms (Broom and Cavenagh, 2010, 874), as well as constrained by cultural norms such as those related to gender.

1.4. Why does gender matter?

While studies within sociology have been very successful in demonstrating gender differences in terms of how men and women experience their ageing and chronically ill bodies, they have not given sufficient attention to the embodied character of gender at end of life. A potential ‘degenderisation’ of patients near death has been proposed by Lawton (2000), who argued that patients lose their capacity to do gender - namely through sexuality and sexual functioning. A binary conception of gender in which it is either lost or maintained was presented by Lawton. She might have overstated the centrality of sexuality in the performance of gender at end of life (Broom and Cavenagh, 2010: 870). The first attempt to counter the paucity of research on masculinities and dying was made by Broom and Cavenagh (2010). The authors have however neglected the influence of feminine identities within the dying process. The process of bodily deterioration and decay might be experienced differently by men and women and further research is needed to explore this. The gender dimension might be particularly relevant for the experience of dying and its bodily realities in Portugal as it has been a country profoundly marked by a traditional conception of what it is to be a man or a woman (Andreotti et al., 2001; Karin et al., 2001; Lopes, 2006; Moreno,

2006). Therefore the purpose of the current study will be to offer insights on the embodied character of gender at end of life.

1.5. The special case of Portuguese society

In contrast to the UK, and most Central and Northern European countries, Portugal, like other Southern European countries, has been characterised by a familistic culture (Jurado-Guerrero and Naldini, 1996; Reher, 1998), where strong family ties persist (Dykstra and Fokkema, 2010; Karamessini, 2008 Tomassini et al., 2007). As a way to understand the nature of this country and this specific group of countries, it is necessary to comprehend their historical specificities. It is fundamental to take into account the role of Catholicism. Despite the secularization processes, the Catholic Church still plays a strong role in Portugal and it is likely to promote traditional family-oriented values (Tavora, 2013). The Protestant Reformation facilitated and influenced the transformation of individual and familial life that took place in the Centre and North of Europe, in particular in the UK. The Reformation called for the power of the individual and emphasised the role of work. The effects of the Industrial Revolution which was based on an ethic in which economic rationality and creativity of individuals was paramount also contributed to the differences between, for example, Portugal and the UK, regarding individual and familial values (Reher, 1998). The Industrial Revolution began in the UK long before it took place in Portugal.

Familism draws on the assumption that the family should be responsible for the welfare of its members (Tavora, 2012). This ideal is historically rooted in rural societies, where

the family worked together to subsist (Aboim, 2010). In practice, this means that the care of children and young people as well as of the elderly is usually delegated to families, in particular to women (Andreotti et al., 2001). Despite the high rate of participation of Portuguese women in the labour market, the bulk of domestic work still falls to them (Lopes, 2006). The patterns of support in Portugal are highly gendered and centred on blood relatives (Karin et al., 2001). The relevance of kin relations within Portuguese society has recently been demonstrated by Aboim et al. (2013), who argued that close relationships persist in Portugal in terms of interactional, emotional and materially based support. Indeed family ties, personal and support networks in Portugal are very much dependent on relationships generated within nuclear families of origin and procreation.

What is very interesting in Portuguese society is that it shows that the increasing individualisation and pluralisation of families are not incompatible with the significance of family relations and support (Aboim et al., 2013). This could suggest that given Portuguese familistic culture, families might be very likely to be present during the dying process. The research about the interplay of family, palliation and experiences near death has been limited. It is therefore important to explore how culture shapes and constrains the dying experience as a social and relational process (Broom and Kirby, 2013). The current study aims to make an important contribution to sociological literature by studying the process of bodily deterioration and decay in a familistic culture such as that of Portugal.

1.6. Palliative care in Portugal: An overview

Almost thirty years after the opening of the St. Christopher hospice in the UK, palliative care began to take its first steps in Portugal. In 1992 a chronic pain unit was created at the hospital of Fundão, a small town in central Portugal. The unit offered in-patient services for advanced cancer patients. Two years later the first palliative care service was established and provided in-patient care to cancer patients from the Portuguese Institute of Oncology, in Porto (Gonçalves, et al., 2014). The number of palliative care services increased slowly. The first home-care team was founded in 1996 at the health centre of Odivelas, in the Lisbon area. In 2001, the Portuguese Institute of Oncology in Coimbra opened its palliative care unit and a palliative care team was created at the Charitable Institution Saint Mercy House of Azeitão - the first outside the public funded national system. That same year, a National Oncology Plan was approved as well as a National Plan for the Control of Pain (Capelas and Coelho, 2014). The first National Palliative Care Plan was issued in 2004 by the Portuguese Ministry of Health. This was an important hallmark for palliative care as it was the first governmental attempt to stimulate the development of palliative care in the country (Neto et al., 2010).

In 2006, a law that created a National Network for Integrated Continuity Care was passed. This programme for chronically ill people included not only long term services but palliative care (Gonçalves et al., 2013a). This was a powerful catalyst for palliative care development in Portugal, although the resources allocated to it are still scarce and do not cover the needs of the population. Indeed according to data from the Portuguese Palliative Care Association in 2011 there were twenty one palliative care teams in the country, which included in-patient palliative care services, hospital palliative care

support and domiciliary palliative care teams for patients and their families (Gonçalves et al., 2014). The inclusion on the list of the Portuguese Palliative Care Association is dependent on the meeting of certain criteria according to international guidelines such as the fact that the team must ensure access to the palliative care drugs recommended by the World Health Organisation and its core members must have undergone advanced education in palliative care (Neto et al., 2010). This latter point could be problematic as palliative medicine is not a recognised speciality in Portugal unlike in other countries such as the UK. This means that the professionals who work in palliative care teams do not have a formal speciality in palliative care or in palliative medicine (Gonçalves et al., 2013a). In recent years, several Masters and intensive short courses have been developed in order to train professionals in this field in order to minimize this gap.

Despite the fact that palliative care in Portugal extends to people suffering from illnesses other than cancer the majority of people who die with the support of palliative care services suffer from cancer. The most common is colorectal cancer, gastric, head and neck, breast and lung cancer (Gonçalves et al., 2013a). Pain has been found to be the most prevalent symptom in palliative care patients (Gonçalves et al., 2013b), following by fatigue, depression/sadness, anxiety and anorexia. Nausea and vomiting are not the most prevalent symptoms within this population (Gonçalves et al., 2004). The medium age of patients is 71 years and most of them are expected to live more than one month with one-third expected to live more than three months after their admission into in-patient palliative care services. This means that the majority of patients supported by these services are not in their last days of life (Gonçalves et al., 2013a).

1.7. The aims of the thesis

As noted above, given the theoretical and empirical neglect of the experiences of in-patient hospice patients and how their deteriorating and decaying bodies might influence this the main focus of the current study will be on their embodied experiences. I want to explore the extent to which the sense of self and identity of terminally ill patients is affected by the process of bodily deterioration and decay prior to impending potential death. What I wish to emphasize here is that cultural norms such as those related to gender might influence the ways in which this process is lived, and in doing so I hope to show the interplay of gender at end of life. Also, I want to demonstrate how culture might shape the dying process and processes of interaction at end of life. The studies conducted in other countries, in particular in Anglophone countries, might not reflect the experiences of in-patient hospice patients in Portugal, as well as in the South of Europe, as the way in which the process of bodily deterioration and decay is lived and interpreted might be embedded in context and thereby constrained by particular cultural circumstances. Drawing upon a selected review of the literature, which will be presented in the following chapter, the central focus of the study will be:

- To analyze the extent to which a visibly altered body might affect the sense of self and identity of terminally ill patients;
- To explore the ways in which the loss of bodily autonomy might affect the sense of self and identity of terminally ill patients;
- To ask how gender might influence the experience of living with a visibly altered body and a functionally changed body;

- To consider if, in the light of the bodily realities of dying, a dignified death is something that Portuguese terminally ill patients can realistically hope for;
- To examine if terminally ill patients in Portugal are likely to experience a social death prior their physical cessation.

1.8. Theoretical framework

The current study is grounded in the interpretative approaches of symbolic interactionism and social constructionism as I seek to understand the extent to which the sense of self and identity of Portuguese terminally ill patients is affected by the process of bodily deterioration and decay prior to impending potential death. The self refers to the interior of the person, while identity is externally dictated (Lawton, 2000: 4). A person is, according to Giddens (1991), composed of a self and an identity, which means that one is dependent on the other and vice versa. Thus, symbolic interactionism would allow me to understand how meanings about the self are developed and transmitted through social interaction (Rozario and Derienzis, 2009).

In addition, social constructionism, which builds on symbolic interactionism, will allow me to examine how identities are shaped and constrained by wider society, namely by its institutions and belief systems (Kelly, 2007). The major advantage of this approach is that it will enable me to examine ‘how, when and to what extent the studied experience is embedded in larger and often, hidden positions, networks, situations and relationships’ (Charmaz, 2006: 130). Furthermore, it will make clear the differences and

distinctions between the different actors within the scenario being studied (ibid). I will draw on these approaches to analyze the data as well as to interpret my findings.

1.9. Structure of the thesis

This study is organised in eight chapters. A selected review of the literature on the bodily realities of illness, ageing and dying is presented in Chapter Two. The Sociology of Death and Dying, the Sociology of Chronic Illness, the Sociology of Ageing, the Sociology of the Body and the Sociology of Emotions provided a valuable framework for responding to the main and subsidiary questions of the study. The methodological aspects of the study are discussed in Chapter Three. The data were gathered by means of ethnographic research strategies. Participant observation was carried out in two palliative care units for cancer and non-cancer patients near Lisbon, the capital of Portugal. In depth interviews were conducted with patients, family members and health care professionals.

In Chapter Four (the first of the empirical chapters), the extent to which a visibly altered body affects the self-identity of terminally ill patients is examined. The significance of a visibly altered body and the way in which gender ideals impact upon patients' perception of an altered physical appearance are discussed. In Chapter Five, the ways in which the loss of bodily autonomy affects the self-identity of terminally ill patients are analysed. The ways in which patients deal with the lack of corporeal self-containment and live with the loss of ability to act as the agent of their embodied actions and intentions are also highlighted. The attitudes and beliefs of patients towards being

physically dependent on the help of others are illuminated. Gender differences are discussed whenever appropriate.

In Chapter Six, the extent to which the bodily realities of dying influence a patient's achievement of a dignified death is examined. The indignities experienced by terminally ill patients and how palliative care contributed to restore or maintain their sense of dignity are discussed. In Chapter Seven, a reflection on whether patients are likely to experience a form of social death prior to their physical cessation is presented. The interaction between patients and their family members, as well as with health care professionals is illuminated, with close attention paid to the palliative care environment. In the final chapter, the main findings of the current study are presented, recommendations for future research are made and the implications for palliative care practice are discussed.

Chapter Two

The body in illness, ageing and dying: A selected review of the literature

2.1. Introduction

A selected review of the literature on the bodily realities of illness, ageing and dying will be presented in this chapter. This will provide a valuable framework for understanding how and why the sense of self and identity of terminally ill patients are affected by the process of bodily deterioration and decay prior to impending potential death. As will be outlined in the current literature review, this might be shaped by specific cultural circumstances. While the literature has been very successful in showing how the experience of an ill and ageing body is greatly influenced by gender, it has not given sufficient attention to the influence of masculine and feminine identities within the experience of a dying body. There has been a tendency within the literature to interpret this experience as largely undifferentiated (Broom and Cavenagh, 2010; Howarth, 2007).

As explained in the introductory chapter, Portugal offers an appropriate context to study the embodied character of gender at end of life as it has been a country shaped by profound gender differences (Andreotti et al., 2001; Karin et al., 2001; Lopes, 2006; Moreno, 2006). The limited research on end of life which has suggested a potential 'degenderisation' (Lawton, 2000) of terminally ill patients has been limited to Anglophone countries and thereby one might speculate that empirical findings are explained by the individualistic character of Anglophone culture. Portugal as a country

characterized by a strong familistic culture (Dykstra and Fokkema, 2010; Karamessini, 2008; Jurado-Guerrero and Naldini, 1996; Reher, 1998; Tomassini et al., 2007) also provides an appropriate context in which to study the extent to which familistic values shape the experiences of those who are very ill and at the end of life, as well as of those who accompanied and cared for them.

The present chapter is divided in three main sections; each draws attention to specific themes and concepts which are relevant to the topic under study. As most patients who die with a terminal illness are likely to suffer from a chronic illness, their experience might find some parallels with the experience of chronically ill people. Attention will thus be paid in the first section of this chapter to the literature on chronic illness. This section will outline the ways in which the loss of control over the body experienced by chronic illness may lead to the disintegration of self and identity. In addition to suffering from a chronic illness, those who are near death are likely to be of advanced age. Thus the literature on ageing will be examined in the second section. An insight into the experiences of the ageing body will be provided here. As men and women are likely to experience their bodies differently across the lifecourse, the ways in which men and women experience their ageing and ill bodies will be examined. A detailed consideration of the end of life experience will be presented in the final section. The process of dying and the loss of bodily control will be discussed in detail. The role of hospice and palliative care and the meaning of dignity and personhood will also be outlined. The detailed analysis of this literature leads to a number of subsidiary questions which will be presented at the conclusion of this chapter.

2.2. The body and chronic illness

In this section I will focus on the literature on chronic illness as it provides an understanding of how it is to live with a life-threatening/terminal illness (McNamara, 2001). The experience of having a chronic illness involves the recognition of pain, suffering and, ultimately, death which are commonly seen as distant possibilities (Bury, 1982: 169). The concept of biographical disruption will be explored next as it will help to illustrate how people deal and live with a chronic illness. The symbolic significance of having a chronic illness will then be explored. Thus attention will be paid to studies that have examined the experience of stigma by those who suffer from a chronic condition. The disruptive effect that the experience of having a chronic illness has on one's normal self presentation will be presented in the third section. After I outline the problems that chronically ill people face, I will focus on studies concerned with interpreting how people respond to the onset of a chronic illness. Studies examining the role of emotions and feelings in the experiencing of pain will be outlined in the last part of this section in order to illustrate the extent to which cultural forces - namely gender dilemmas - shape how people live and deal with chronic/terminal illness.

2.2.1. The everyday experience of chronic illness

Bury (1982) has been at the forefront of the literature on chronic illness by describing its onset as a major disruptive event. Drawing upon Giddens's (1979) work, Bury claimed that the development of a chronic illness should be regarded as a critical situation - or what he refers to as a form of biographical disruption. The things that are

taken-for-granted such as bodily states and behaviours are disrupted by the onset of a chronic illness. The development of a chronic illness, he argued, also leads to the profound disruption of an individual's biography and self-concept. Bury's (ibid) work draws some parallels with the work of Charmaz (1983), who used the concept of loss of self to describe the nature of the suffering experienced by the chronically ill. According to Charmaz 'chronically ill persons frequently experience a crumbling away of their former self-images without simultaneous development of equally valued new ones' (ibid: 168).

The idea that the development of a chronic illness dramatically disrupts everyday life has been challenged in the last decade by a number of authors. Simon Williams (2000), for instance, argued that the concept of biographical disruption does not take into account possibilities that may be integral to individuals' biography such as abnormalities and deformities. Thus, S. Williams claimed that the onset of a chronic illness may be a biographically anticipated rather than a disruptive event. This means that although some chronically ill people may find their lives disrupted by the onset of a chronic illness others may see it as part and parcel of an ongoing life story. Sanders et al. (2002) made a similar observation in a study on middle-aged and older men and women with osteoarthritis. They found that some respondents described their symptoms as a normal and integral part of their biography, while others understood it as a major disruption. The experience of symptoms is thus portrayed as both biographically normal and abnormal.

Faircloth et al. (2004) suggested that stroke is not commonly reported as a biographically disruptive event, but it is integrated along with other social contingencies

in constructing a biography that is constantly suffering a number of changes. As Pound et al. (1998) have noted stroke is not always experienced as an extraordinary event. Rather it is viewed as a normal crisis. This is because long before they had a stroke these people experienced personal hardship and illness, as well as the death of their loved ones. A similar observation was made by Sinding and Wiernikowski (2008) who, in their study of the experience of cancer amongst older women, noted that a long life characterized by struggle and hardship provided a context for the assessment of cancer as non-disruptive. This finding was related to the concept of biographical reinforcement proposed by Carricaburu and Pierret (1995) in a study of asymptomatic HIV-positive men. These authors found that HIV-positive men revealed a sense of identity and tried to give continuity to their biography. Thus, it could be argued that, whether chronic illness is conceptualised as biographical disruption (Bury, 1982), biographical continuity (Williams, 2000), biographical flow (Faircloth et al., 2004) or biographical reinforcement (Carricaburu and Pierret, 1994), the point is that in order to understand how people experience and live with chronic illness, one needs to look at an individual's biography. This body of work aids comprehension of the impact that having a diagnosis of malignancy can have on the lives of those who are ill, and ultimately, on the lives of their family.

2.2.2. The significance of having a chronic illness

The concept of biographical disruption developed by Bury (1982), as outlined previously, has thrown light on the ways in which a chronic illness is experienced in the context of daily life. The onset of a chronic illness according to Bury necessarily involves the mobilization of resources as a way to mitigate the disruptions experienced. There are a number of practical consequences which the ill person and his/her family has to overcome, alongside the symbolic significance attached to the fact of having a chronic illness (Bury, 1991). Work on stigma has drawn attention to this latter point. Building on Goffman's (1968) concept of stigma, Scambler (2009) showed how those who suffer from a health problem or a health-related condition experienced a discriminatory social judgment on the grounds of their disease or designated health problem. The concept of stigma as developed by Goffman (1968) refers to an attribute that is deeply discrediting such as the 'abominations of the body'. According to Goffman individuals may suffer from a visible stigma - what he calls discredited - and thereby have to integrate it into social interaction and to cope with social judgments; or they may be afflicted with an invisible stigma - what he refers to as discreditable - and thus have to manage as best they can the information about their condition and decide who to tell about it (Rosman, 2004: 334).

The sense of being imperfect as a result of having a chronic illness such as epilepsy has been explored by Scambler and Hopkins (1986) who, based on their empirical findings, established a distinction between enacted and felt stigma. The former is related to instances of discrimination against chronically ill people on the basis of their unacceptability or inferiority, while the latter is linked to the fear of enacted stigma and

encompasses feelings of shame associated with being chronically ill (ibid: 33). This sense of felt stigma has also been made apparent in Schneider and Conrad's (1980) study of people with epilepsy. Schneider and Conrad showed how children learn from - what they refer to as stigma coaches - parents, friends and professionals how to conceal their illness from others. Scambler and Hopkins' (1986) as well as Schneider and Conrad's (1986) findings, are reinforced by Camp et al. (2006), who explored the extent to which the membership of a stigmatized group has negative consequences for one's self-concept. Unlike Scambler and Hopkins and Schneider and Conrad, Camp et al. (ibid) paid attention to the experiences of people who suffer from a mental illness. Camp et al. found that the stigma faced by women with chronic mental health problems was not something they were responsible for, but it was due to the flaws of those who stigmatize them (ibid: 830). The 'ontological deficit' could also be extended to significant others. This stigma of affiliation has been described by Gray's (2002) study of parents of children with autism, where it was found that because of their children's disability parents experience both felt and enacted stigma.

The concept of stigma has also been used to describe how chronic illness is integrated into one's identity. For instance, attention has been paid to the ways in which HIV-positive people incorporate their new identity within the context of a society that stigmatizes their chronic condition (Baumgartner, 2007). HIV-positive people have been found to experience feelings of being contaminated due to internalized stigma as well as in relation to perceived interactions (Chapman, 2000). These feelings have been similarly experienced by people with cancer (Mathieson and Stam, 1995), in particular with lung cancer, who were found to experience high levels of stigmatization because of

the association between the disease and smoking, and perception of the disease as a self-inflicted injury (Chapple et al., 2004). This body of work has been helpful in illustrating the ways in which chronic illness can be experienced as a stigmatizing condition due to its social associations.

2.2.3. The rupture of a normal self and a normal self-presentation

The onset of serious illness and disability might have a profound effect on the way individuals regard themselves as well as on how they think others see them (Williams, 2000: 44). Taleporos and McGabe (2002) found that the negative feelings and attitudes described by people with physical disabilities concerning their bodies were more often than not a product of their social environment. Their findings support Goffman's (1963) argument that people who possess more salient bodily differences are those who are more severely stigmatized. Taleporos and McGabe's (2002) study draws some parallels to the study of Chau et al.'s (2008) of women living with a spinal cord injury, where it was found that their altered physical appearance resulted in negative reactions from other people, causing feelings of frustration and sadness. As a way to avoid being discriminated on the grounds of their altered body these women decided to isolate themselves.

In his study of people who had had ulcerative colitis cured by radical surgery, Kelly (1992) found that as a way to maintain their ileostomy as a secret these sufferers tried to maintain their ordinary presentation of self. Their viable sense of self might be undermined by unwanted public discourse and as a way to conceal their new identity

they become masters in the art of what Goffman (1968) has called impression management. They feared that ‘once the identity as ileostomist is made plain, other identities as an ordinary, and apparently normal, adult, worker, wife, father, bowls player etc. are themselves called into question by the negative attributes attaching to the ileostomy category’ (Kelly, 1992: 410). Kelly’s work offers a graphic account of the struggles experienced by the chronically ill in order to maintain a normal self and a normal self-presentation.

The body in both Kelly’s (1992), Chau et al.’s (2008) and Taleporos and McGabe’s (2002) study is thrown into light as it had become visible due to the possession of an altered physical appearance. The body, albeit in a dysfunctional sense, had become a central aspect of experience (S. Williams, 1996). This body of work served to underline how an altered physical appearance contributes to patients’ feelings of being discredited by other people. I will return to this discussion in Chapter Four where I examine how patients feel negatively evaluated by others on the grounds of their visibly altered bodies.

2.2.4. Making sense of chronic illness

The way people experience a diagnosis of malignancy is not only influenced by the social context in which they live, and the nature of their symptoms, but by the perception by self and others (Bury, 1991). Therefore there is the need to understand how people legitimate and explain the disease. The literature has been successful in understanding the problems that people experience in the face of a chronic illness, as

well as in interpreting how they responded to it (S. Williams, 2000). Bury (1991), for instance, has drawn some useful distinctions. Coping, for Bury, refers to cognitive processes whereby individuals learn to tolerate their illness and its effects. The term relates to feelings of personal worth and a 'sense of coherence' in the face of disruption. Normalisation, for example, as a form of coping refers to the psychological bracketing off of the impact of the illness as a way to minimize the effects on the person's identity. Strategy is related to actions that individuals take in the face of their illness. The concern here is on the actions taken to mobilize resources and maximise favorable outcomes. Style refers to how individuals respond to and present features of their illness, treatment or treatment regimes. This involves the cultural repertoires that people can draw upon in presenting their altered physical appearances and social circumstances (ibid: 460-462).

This latter point was widely discussed by Radley (1989) in his study of coronary heart patients. Radley distinguished between two models of adjustment: accommodation and active denial strategies. The former 'occurs where roles are more flexible and where choices about how symptoms are to be presented can be developed through elaborated communication with others', while the latter 'involve the adoption of a style where illness is opposed through increased engagement in everyday activities and where communication is more restricted in character' (Bury, 1991: 463). For Radley 'the bodily and social constraints which are to be resolved in the course of any adjustment to illness need to be located in the practices and in the discourse of the people concerned' (1989: 233). Drawing upon Bourdieu's (1984) work on class-related habitus, Radley argued that 'people's adjustment to chronic illness is not adaptive in principles, in the

sense that it simply restores an equilibrium or status quo' but 'an ongoing discourse and set of related practices' (1989: 248).

Radley's (ibid) approach to chronic illness may provide valuable insights into studies that have focused on the roles of narrative to understand how chronically ill people respond to the illness. The narratives in Gareth Williams's (1984) study, for instance, 'may be seen in the light of the links between social class, social practices and style' (Bury, 1991: 463). G. Williams (1984), in his study of people who have been diagnosed with rheumatoid arthritis, argued that the onset of a chronic illness necessarily requires the development of an explanation on the part of those who suffer. He found that when asked about the cause of their chronic illness most ill people found no meaning in the medical world and as a consequence added a moral and social component to their explanations. G. Williams concluded that through the reconstruction of their experience chronically ill people are able to 'bridge the large gap between the clinical reductions and the lost metaphysics' (ibid: 197). According to G. Williams 'once you begin to look at causal models as narrative reconstructions of the genesis of the illness experience in the historical agent, moral or religious, indeed, political and sociological factors become central to elucidating illness experience and rendering intelligible the biographical disruption to which it has given rise' (ibid: 197).

G. Williams's discussion of biographical disruption as a cause of chronic illness calls attention to the 'role of live events in the aetiology of disease, both physical and mental' (S. Williams, 2000: 53). 'External structural factors such as one's position in different systems of hierarchy or various forms of social control can influence the conditions of our existence, how we respond and apprehend these conditions and our sense of

embodied self' (Freund, 1990: 461). Feelings in this light are very much related to the conditions of existence encountered throughout one's biography. This leads to the need to understand the extent to which our emotions are attached to our embodied biographies (S. Williams, 2000).

2.2.5. The intersection between biology and culture in the experience of illness and pain

Through a focus on emotions I aim to understand the complex ways in which people experience chronic/terminal illness. Consideration of the role of emotions and feelings in the experiencing of pain provides a valuable framework. Pain is indeed a central aspect of the experience of living with a chronic, and ultimately, terminal illness. The sociological work on pain has drawn attention to the fact that body and mind are interwoven in pain and thereby that the physical experience is inseparable from its cognitive and emotional significance (Bendelow and Williams, 1995: 151) The medical discourse of pain which focuses on physical sensations thus should be seen as just one voice among many others (Bendelow, 2006). The Cartesian split between body and mind, which has led to a reductionist categorization of a person's pain into symptoms, has been challenged. Bendelow and Williams (1995), for instance called for 'an approach which sees pain as physical and emotional, biological and cultural, even spiritual and existential' (ibid: 160). This notion has been at the heart of the concept of 'total pain', proposed by the proponents of the modern hospice and palliative care movement, which in its formulations included physical, psychological, social and spiritual elements (Clark, 1999).

Conceptualizations of pain within the sociological literature (e.g. Bendelow and Williams, 1995) have not only challenged the reductionist medical assumption of pain as a physical sensation, but have thrown light on the ways in which culture shapes the interpretation and meaning of pain. This is important work in that it shows how gender influences perceptions of pain and eventually the experience of living with a serious and advanced illness. For example, Bendelow (1993) found that women are more likely to present holistic, integrated notions of pain than men. Men tend to ascribe a 'hierarchy of respectability' to types of pain and are reluctant to consider emotional pain as 'real' pain. Both women and men interviewed by Bendelow expressed the view that girls and adult women are equipped with a natural capacity to endure physical as well as emotional pain. This according to them was related to women's reproductive role and to female biology. Nevertheless, Bendelow noted that such explanation was not only underpinned by biological principles, but embraced sociocultural themes of roles and socialization. The role of motherhood has also been found to be at the heart of these assumptions. In contrast to what tends to happen in relation to women, there is not a cultural expectation placed upon men to express pain, as they are discouraged from an early age to do so.

This body of work has overall called for the need to comprehend the biographical, social and cultural contexts in which pain is located and experienced as a means to understand it (Clark, 1999). Bendelow's (1993) work, for example, offered valuable insights into the ways in which understanding and responding to pain is primarily linked to gender-differentiated processes of socialization (Bendelow and Williams, 1998: 265).

Thus it draws attention to the fact that the experience of embodiment is shaped and constrained by a variety of cultural circumstances, such as those related to gender.

2.3. The body and ageing

The ways in which both men and women experience their bodies is very much linked to processes of socialization and enculturation. The literature on ageing provides valuable insights into how biology intersects with culture and thereby attention will be given in the present section to ill ageing bodies. This is important work in that it demonstrates how the body is culturally constructed and how gender might influence bodily experiences. Individuals are able to construct and express their versions of ageing and age resistance and thereby studies that have explored this issue will be examined. As men and women might face different pressures regarding their bodies, studies that illustrate how gender norms intersect with ageing and ageing bodies will be outlined. The ways in which gender shapes and constrains the experience of an ill, dying body will also be analyzed.

2.3.1. The cultural construction of the body in later age

It is in and through our bodies that we experience the realities of growing old (Hurd Clarke and Korotchenko, 2011: 495) - this might be best understood through the concept of embodiment as proposed by Merleau-Ponty (1962). For Merleau-Ponty embodiment is 'the very basis of experience. We experience by way of our (sentient) embodiment. Our body is our way of being-in-the-world. It is our point of view of the

world' (Crossley, 1995b: 48). This means that individuals not only have bodies but that they are their bodies (Turner, 1984). Thus, experiences of ageing, whether it refers to social or physical aspects, are necessarily embodied (Hurd Clarke and Korotchenko, 2011).

The construction of later life identities in the past few decades has become deeply interwoven with the discourse of successful ageing (Higgs et al., 2009; Lamb, 2014), which calls for the ability to avoid disease and disability, to maintain physical and cognitive functions and to engage in social activities (Rowe and Kahn, 1997; Duay and Bryan, 2006). Thus having a health condition in later life is seen as a failure to age successfully (Hurd Clarke and Bennet, 2013b) and a marker of entrance into the so called Fourth Age - a time that is characterised by frailty and dependency (Higgs et al., 2009). In contrast, the Third Age is seen as a time when older people are able to engage in meaningful activities and thus to achieve a sense of fulfillment (ibid: 689). The distinction between the Third and the Fourth Age is qualitative and not chronological in nature - the onset of a serious infirmity is what marks the transition from one to the other (Twigg, 2004).

The Fourth Age carries with it the notion of passing beyond the social world and thereby it has been described as a black hole (Gilleard and Higgs, 2010b). The Fourth Age functions as a social imaginary as it does not represent a particular stage of life per se but a kind of terminal destination. That is, 'a location stripped of the social and cultural capital that is most valued and which allows for the articulation of choice, autonomy, self-expression, and pleasure in later life' (ibid: 123). The Fourth Age is thus rooted in the fear of loss of agency and bodily control (Gilleard and Higgs, 2011). The

Fourth Age is based on a set of assumptions regarding the dependencies and indignities of real age, whereas the Third Age is a generationally defined 'cultural field' which is very much concerned with the everyday practices of older people (Gilleard and Higgs, 2013).

The discourse of successful ageing - which can be integrated into this cultural field - encourages individuals to 'take control of their own ageing by maintaining themselves as healthy, productive, active and independent' (Lamb, 2014: 46). This, on the other hand, draws on 'a distinctive cultural model of personhood, featuring individual agency, independence, productivity and self-maintenance' (ibid: 46). The notion of the individual self as a project is thus central to such a conception of personhood (ibid). In order to highlight this conception of self I will now turn to a detailed consideration of the construction of later life identities within the context of consumer society.

2.3.2. The ageing body in light of consumer culture

Within the context of consumer culture the body has become a project that needs to be worked on and accomplished as part of an individual's self-identity (Shilling, 1993). Self-identity and the body have thus become reflexively organised projects for which the individual is responsible (Giddens, 1991). This led to the development of 'individualized' cultures of ageing where individuals are able to construct and express their versions of ageing and age resistance (Gilleard and Higgs, 2000). The possibility exists for individuals to create new identities outside of those recognised by the traditional life stages and to access the means to resist the appearance of growing old

(Ballard et al., 2005: 170). Featherstone and Hepworth (1991: 375) in their mask ageing theory argued that the ageing process is no more than a mask which conceals the youthful self beneath. This contrasts with Biggs's (1997: 566) theory on the persona or social mask, which claims that a mature identity leads to the wearing of a mask that evokes a more youthful façade.

The validity of the idea of the ageing mask and of the notion of persona or social mask was questioned by Ballard et al. (2009) in their study with middle aged women about their experiences of menopause. Ballard et al. argued that both theories have focused on what they called public ageing - which refers to the visible, physical age-related changes in the body. These authors found that women also spoke about their private ageing experience - which is related to the less visible, physiological changes in the body. The desire to conceal the physical signs of ageing led these women to participate in age-resisting activities, namely what Gilleard and Higgs (2000) referred to as passive acts of consumption like occasional hair colouring and the use of anti-wrinkle creams. These women were committed to presenting an image that reflected their subjective experience of growing old and at the same time was socially acceptable. Women's desire to resist their changing appearance was however limited by the obduracy of the body experienced in private ageing. That is, the perceived rigidity of the body in private ageing influenced their motivation to participate in age-resistance activities (Ballard et al., 2005).

The participation in age-resistance activities that compels women to make their chronological ages imperceptible have been found by Hurd Clarke and Griffin (2008) to be instigated by the social invisibility derived from the acquisition of visible signs of

ageing. These authors noted that women's ageing appearances were pivotal to their lived experiences of ageism. Ageism refers to stereotyping and discrimination against individuals because of their age (Butler, 1969) and draws upon the societal obsession with youthfulness which characterises consumer culture (Featherstone, 1991). The possession of an aged appearance rendered the women in Hurd Clarke and Griffin's (2008) study more visible as objects of discrimination as they deviated from youthful beauty standards. The visible signs of ageing like wrinkles, grey hair and sagging skin led these women to become socially invisible. Thus by making these markers less visible to others through various forms of beauty-work they were able to become more socially visible and valued. Hurd Clarke and Griffin's (ibid) work offers a valuable insight into the stereotypes concerning older women and physical attractiveness. I shall now turn to more detailed consideration of how gender shapes the experience of an ageing body.

2.3.3. Gender and the ageing body

The pressure that men and women face to maintain bodies that are young looking is not equally experienced, as the ageing of women and women's bodies is more socially sanctioned (Hurd Clarke et al., 2008). There is, as Sontag (1972: 31) pointed out, a 'double standard about ageing' as society is much more accepting of the ageing of men than of women. Women tend to experience ageing in more painful ways than men due to cultural standards of female beauty. Indeed as women age they are no longer able to maintain and achieve the idealized female body which is thin, toned, shapely and young (Hurd Clarke et al., 2008; Bordo, 1993). Thus, women end up losing their sexual

attractiveness and, ultimately, their social currency (Brown and Jasper, 1993; Sontag, 1972). Women learn from an early age that they are evaluated by other people on the basis of their physical appearance (Hurd Clarke and Griffin, 2007; Franzoi, 1995). In contrast to women's 'body-as-object' orientation, men tend to follow an instrumental orientation towards their bodies and thus to perceive function as a more important aspect than sexual attractiveness (Cash and Brown, 1989; Franzoi et al., 1989; Franzoi, 1995). I will return to this line of discussion in Chapter Four where I analyze the importance of physical appearance to men's and women's sense of self and identity.

The internalization of these gender norms had become apparent in the literature on ageing. For example, Hurd Clarke et al. (2008), in their study on body image and multiple chronic conditions in later life, found that the older men who expressed discontent with their bodies tend to focus on their changing physical abilities and thus to speak about their bodies in terms of a process. These men's discourse on how to handle the physical realities of later life seemed to reflect masculine norms, namely the need for strength, action and autonomy. In contrast, older women indicated that the appearance of their bodies influenced their felt ages and made them feel that they were no longer attractive to members of the opposite sex. Women's dissatisfaction with the appearance of their ageing bodies, namely with their weight gain/loss, became very prominent in Hurd Clarke's (2002) study on older women's body image. The decline in health and physical abilities did not lead, as one might expect, to these women valuing physical function over physical attractiveness. The dissatisfaction with weight indicated by the women in Hurd Clarke's study (*ibid*) was spoken about in terms of their

appearance. This led to the conclusion that appearance is a central issue for many women in later life.

In addition to discontent with their appearance, Hurd Clarke and Bennet (2013a) found that older women who had multiple chronic conditions have concerns about the ways in which their ill bodies might affect their loved ones. This was linked to expected feminine qualities that privileged selflessness, nurturing and sensitivity to others (ibid; Prentice and Carranza, 2002). In contrast, the older men with multiple chronic conditions interviewed by Hurd Clarke and Bennet (2013a) indicated that their dependence on others was a source of personal frustration as it contradicted masculine norms of control, autonomy and invulnerability (ibid; Prentice and Carranza, 2002). These feelings were augmented by their growing dependence on the women to whom they were close. The achievement of such masculine ideals - those of control and invulnerability - have also been found to be at the heart of the experience of self-care by older men who had multiple chronic conditions in another study by Hurd Clarke and Bennet (2013b). On the other hand, older women's use of self-care was driven by the desire to reduce the burden they placed on their loved ones and thereby it seemed to be in accord with feminine ideals, namely those of selflessness and sensitivity to the needs of others.

Women's fear of becoming a burden to significant others has also been found to be a major issue in Arber et al.'s (2008) study. These authors noted that older women expressed 'other-oriented' reasons for their opposition towards the use of medical technologies for themselves as they were concerned about the consequences that the extent of their life could have on their family. In contrast, older men indicated 'self-

oriented' attitudes towards the use of life-prolonging technologies in the sense that they were concerned to stay alive as long as possible irrespective of the consequences that this could have on their significant others. What this body of work particularly reveals is that the experience of chronic conditions in old age is gendered as older men and women respond to their physical limitations differently (Hurd Clarke and Bennet, 2013a), and in doing so it provides valuable insights for the theorizing of chronic illness in later life. As the experience of living with a chronic condition has been found to be profoundly gendered and influenced by masculine and feminine norms (ibid) it is surprising that few studies have outlined the role of gender and of male and female identity at end of life. Thus it is to a more detailed consideration about this matter that I will now turn.

2.3.4. Gender and the ill, dying body

Research on older adults' attitudes toward death and their experiences of the dying body has been scarce (Hurd Clarke et al., 2012). The functional limitations that accompany old age more often than not culminate in a profound awareness of finitude (Nicholson et al., 2012). The ways in which older adults confront and deal with dying and its bodily realities may be profoundly marked by gender differences. There has been however within the literature a tendency to ignore the interplay of gender with end of life experiences. The thesis that gendered differences are not marked amongst patients who are near death (Lawton, 2000) has been recently challenged by Broom and Cavenagh (2010).

Broom and Cavenagh (ibid) demonstrated that feeling like a burden and losing one's independence had a more detrimental impact on male patients than on their female counterparts. These authors argued that there is an incompatibility between the 'slow death' and male identity. They found that the ability to maintain the masculine status within the dying process is central for men's willingness to perform the 'good fight' against death. Lawton (ibid) has touched on the role of gender at end of life by suggesting a potential 'degenderisation' of hospice patients through their loss of capacity to do gender (Broom and Cavenagh, 2010: 870). The fact that hospice patients had lost body parts related with sexuality and sexual performance due to cancer treatments had according to Lawton (2000) led to a disinvestment in their masculinity and femininity. Lawton's thesis implies that all hospice patients had gone under a surgical procedure or another type of treatment which had led to a loss of their sexual functioning.

Lawton, according to Broom and Cavenagh (2010: 870), had overstated the centrality of sexuality in the performativity of gender at end of life and had focused on a binary conception of gender in which gender identity is either lost or maintained. Lawton (2000) indeed argued that 'to lose one's sex is to lose both gender and sexuality simultaneously, for the one implies the other inexorably' (ibid: 168). Lawton's findings are however not in accord with those of other studies, which explored the ways in which cancer and its treatments affect patients' bodies and their sense of femininity and masculinity. For example, Bredin (1999), Crouch and McZenzie (2000) found that women who had had a mastectomy due to breast cancer did not experience a total disinvestment in their sense of womanhood as long as they were able to conceal their

bodily disfigurement. These findings are similar to those of Chapple and Ziebland (2002), who observed that men who have had surgical and radiotherapy treatment for prostate cancer, unlike those who have had hormone treatment, did not report that their limited sexual function had affected their sense of masculinity. These men talked about this issue as a 'small price to pay'. Chapple and Ziebland concluded that it is not the side effects of prostate cancer treatment, which eventually may lead to sexual dysfunction, that intrude most on men's sense of masculinity, but hormone therapy per se as it constrains the way men and women react to each other and how roles are played (ibid: 838). This reminds me of West and Zimmerman's (1987) theory that 'a person's gender is not simply an aspect of what one is, but fundamentally it is something that one does, and does recurrently, in interaction with others' (ibid: 140). For West and Zimmerman 'it is individuals who do gender. But it is a situated doing, carried out in the virtual or real presence of others who are presumed to be oriented to its production' (ibid: 126).

The men diagnosed with testicular cancer in Gurevich et al.'s (2004: 1605) study indicated that although testicular excision signifies a loss of masculinity it also represents an escape from the rigidity of what it means to be a man. These men by providing accounts that defy emasculating readings of testicular cancer indicated the need to question the meaning of embodied maleness as well as the relation between male identity and sexuality. This body of work convincingly demonstrated that the construction of men's (and women's) gender is far from static (Kelly, 2009) and alluded to Courtenay's (2000: 1388) thesis that men (and women) are not passive victims of prescribed social roles, but are powerful agents in the production of masculine (and

feminine) scripts. While the literature has been successful in showing gender differences in terms of how men and women experience their ageing and chronically ill bodies, it has not been elucidative in relation to the death and dying experience. Indeed there is an empirical gap in the understanding of the interplay of gender and end of life experiences. I attempt to remedy this in Chapter Five, where I examine how the loss of bodily autonomy prior to impending potential death affects men's and women's sense of self and identity.

2.4. The body and the dying process

In this last section attention will be paid to the manifestations of bodily deterioration and decay alongside the dying process and how this constrains processes of interactionality. I will begin by discussing the unboundedness of dying and how palliative care might control (or fail to control) bodies that are disintegrating. The impact that caring for an unbounded dying body might have on significant others will also be analyzed and in doing so I will demonstrate how this might shape palliative care admission. The philosophy of palliative care will be outlined here through discussion of the revivalist good death ideal. Studies that have recognized cultural diversity amongst good death discourses will be discussed. As families might be clearly implicated in the discourse of a revivalist good death advocated by palliative care proponents, attention will also be given to family dynamics at end of life. As I show how families might be more supportive in less individualistic countries, I then question the relation between bodily autonomy, personhood and dignity at end of life, as this might be shaped by familistic values and thereby individual (bodily) autonomy might not be a core value for personhood and one's sense of dignity.

2.4.1. The preferred place of death and the unbounded dying body

Despite the desire of those who are very ill and at the end of life for a home death, this might not always be achievable due to corporeal matters, namely symptom management and pain control as well as the maintenance of personal dignity and identity in the face of loss of bodily control (Thomas et al., 2004). Home has indeed been found to be an

inappropriate space to deal with an 'unreliable body' (ibid) or what Lawton (2000) had described as the 'unbounded dying body'. As Seale (1995: 389) pointed out, the placement of the dying person in an institution - whether a hospice, a hospital or a nursing home - can be understood as a practice that contribute to what Elias (1994: 114) had referred to as the 'civilizing process' in the sense that natural functions, such as defecating, urinating and spitting are 'contained' and 'hidden' from the community.

The 'unbounded body' is perceived symbolically as a source of dirt (Lawton, 2000) or what Douglas (1966) had called as 'matter out of place' - something which had to be removed from mainstream society. Drawing on Douglas' (1966) work on the symbolic systems of purity, Lawton (2000) explained how modern western society had become intolerant towards bodily deterioration and decay. Lawton identified a subgroup of terminally ill patients whose body surfaces had ruptured and broken down and who as a result were sequestered within hospices. Lawton found that patients who suffered from urinary incontinence, repeated vomiting or diarrhea, weeping limbs and fungating tumours at the time of hospice admission were able to return to their homes after these symptoms were controlled and their bodies had thus been successfully 're-bounded'. The patients who remained at the hospice until they died were those whose fluids and bodily matters remained uncontrolled, such as patients who suffered from faecal incontinence.

Lawton's (ibid) findings were not surprising as the hospice where she carried out her fieldwork was undergoing a turbulent time in which the staff were expected to discharge patients after a one or two week period of stay, due to bed shortages. The patients who remained at the hospice for a longer period, and eventually died, were those who

required symptom control and thereby were not able to be discharged. Nevertheless, Lawton did not acknowledge how this had affected her own observations and had led to her conclusion that the hospice is a mediator between the unbounded and bounded dying body. The hospice according to Lawton (1998) 'served to impose order upon disorder through enclosing and containing the odours emitted from patients' disintegrating bodies within a bounded space' (ibid: 134). Indeed Lawton argued that the hospice is a 'no-space' as it enables that 'certain ideas about living, personhood and the hygienic, sanitized, somatically bounded body to be symbolically enforced and maintained' (ibid: 139).

In a similar way to Lawton, Froggatt (2001) found that the deterioration and decaying of the body could explain why some older people were set apart from others in nursing homes. Indeed Froggatt observed that when the unboundedness of their bodies became evident older people were taken aside from public areas in order to reinstate the boundary. This was common in situations where pads were not sufficient to create a boundary against the unboundedness of urine. The signs of body breaching would be taken away with a change into clean clothes and dry pads. In the case of weeping wounds new dressings were applied to contain the presence of unwanted bodily fluids. The sequestration of unboundedness is however not exclusive to institutional settings as it has been found by Brittain and Shaw (2007), in their study on carers of stroke survivors who suffer from incontinence, that the home itself can become a container of unbounded bodies within the community and thereby confine the survivor and the carer to the home-space.

Brittain and Shaw's (ibid) work suggests that those who had bodies which remained unbounded were likely to experience a form of social death prior to their physical cessation. This was so because due to the embarrassment of leakage and the moral danger of odour the stroke survivor and the carer socially isolated themselves within their own home and discouraged others from visiting them. The term social death was originally formulated by Sudnow (1967) to refer to the point when an individual began to be treated as already dead despite being biologically alive. The social isolation experienced by stroke survivors and carers in Brittain and Shaw's (2007) study shows some parallels with that experienced by hospice patients in Lawton's (2000) study. Lawton, for example, found that patients who have bounded bodies were likely to avoid being in the same space as patients who have lost control over the physical boundaries of their bodies. Lawton's (ibid) findings are reminiscent of those of Payne et al. (1996a), who noted that the witnessing of unpleasant symptoms in fellow hospice patients was perceived to be very distressing. The patients in Lawton's (2000) study whose bodies remained unbounded were labeled by others as vulnerable, polluting and dangerous and thus became the subject of taboo.

Lawton (2000) thus suggested that the hospice is a kind of a liminal space where patients felt themselves to be in a suspended state. This suspended state was also spoken about by Murphy et al. (1988) and Mwaria (1990) in their studies on the disabled and patients in coma or in a persistent vegetative state who were found to be in a socially ambiguous and isolated position. Van Gennep (1960) and Turner (1969) described this state as a 'betwixt and between position' in which individuals have been expunged from their old status and have not yet acquired a new one. The patients in Lawton's (2000)

study indeed no longer considered themselves or were considered by others as a person as they contradicted cherished classifications of what it means to be a person in a context such as modern England (please see section 2.4.5. for a detailed consideration about this issue). That is, because hospice patients have not only lost the capacity to maintain control over their physical boundaries, but the ability to act according to their wishes and intentions - i.e. their bodily autonomy - and thus were no longer able to perform certain tasks and to engage in meaningful interactions that enable them to be considered as persons.

Lawton's (ibid) argument that the hospice is a kind of liminal space appears to be simplistic as she did not take into account that the hospice may offer a space where patients can gain a certain degree of control over the dying process (Broom and Cavenagh, 2011). Broom and Cavenagh (2010), for example, found that from the perspective of terminally ill patients one of the major benefits of hospice care was the control of their bodily manifestations. These authors observed that for those who suffered from pain, incontinence of urine or breathing troubles the admission into the hospice enabled the maintenance of a degree of functionality and at one and the same time the opportunity to spend time with their loved ones without the concerns of being a burden on them. On the other hand, for patients who suffered from other types of symptoms such as paralysis or faecal incontinence hospice care was not able to reconstitute them as functional and thereby did not enhanced their sense of personal control or offer space for a more desirable dying process (ibid: 874). Broom and Cavenagh's (ibid) work contradicted Lawton's (2000) theory that hospices served exclusively to accommodate patients whose bodily boundaries had ruptured and broken

down permanently. I will return to this line of discussion in Chapter Six, where I outline the different experiences of bodily disintegration at the hospice and the ways in which the hospice may be able to accommodate it.

2.4.2. Caring for the unbounded dying body

The impossibility of managing complex symptoms at home has been found to be at the heart of hospice admission (Broom and Kirby, 2013). This echoes findings from previous studies on the expectations of end of life care by elderly people. The management of the dying body at home was a major concern expressed by older people in a study conducted by Seymour et al. (2007). These respondents were particularly worried by the contamination of home by death and the dying body. The belief that if symptoms are not adequately controlled it is better for the dying person not be cared for at home was also indicated by older people in Gott et al.'s (2004) study. It has indeed been found by Angus et al. (2004) that the homes of ill elderly people are not able to adequately accommodate their needs. This has been similarly observed in relation to the care of those who are very ill and at the end of life, as home is more often than not seen by dying people as a place of potential loss of control over their disintegrating and decaying body (Broom and Cavenagh, 2011). In addition to fears about the loss of control over what Lawton (2000) has called the 'unbounded body' and the consequent contamination of the home environment, worries about being a burden to family and the caring skills of family carers have also been found to influence hospice admission at the time of dying (Seymour et al., 2007; Gott et al., 2004; Broom and Cavenagh, 2011; Broom and Kirby, 2013).

When personal care needs became too much for one's family the dying person may feel an urge to leave home to be cared for in an institutional setting (Broom and Cavenagh, 2011; Broom and Kirby, 2013; Gott et al., 2004; Seymour et al., 2007). The admission into the hospice is in this light understood as a necessary means to alleviate the burden placed by the dying person on their family (Broom and Cavenagh, 2011; Broom and Kirby, 2013). Self-perceived burden indeed has been found to be a major concern for people who are near the end of life and has been linked with the sense of dependence that accompanied their poor health (McPherson et al., 2007). Within a discourse of 'independence', which places great value on self-sufficiency, the need for others' help is constructed as burdensome (Breheny and Stephens, 2012).

By accepting their admittance into the hospice, patients are able to exercise choice over who can be involved in the care of their unbounded dying body (Chattoo and Ahmand, 2008). The personal and intimate nature of caring indeed has been found to be a major concern to those who are very ill and/or at the end of life (Gott et al., 2004; Hurd Clarke et al., 2013; Seymour et al., 2007). Seymour et al. (2007) and Gott et al. (2004), in their studies of older people's attitudes towards the provision of end of life care at home, noted that the provision of personal and intimate care by adult children was something that older people wished to avoid. This could be explained by the sexual taboo 'which defines any contact, whether opposite sex or same sex, with another person's naked or near naked body outside the conjugal relations as immoral or at least sexual' (Wong, 2005: 384). The taboo is even more augmented in the context of the relationship between parents and their children as the sexual contact between them is viewed as incest (Twig, 2000).

The exposing and touching of one's own body has been found to be a source of stress for both the care recipient and the care provider due to the sexualized meanings of the body as well as the gendered character of body care (Wong, 2005). As body work has been considered to be mainly women's work, bodily dimensions and images of care work might have different implications for men and women (Widding Isaken, 2002: 792). This means that the caregiving of elderly/dying parents could be particularly difficult to perform by sons as opposed to daughters (Allan, 1988), as traditionally women have been responsible for the care of babies and young children within the family (Twigg, 2000). The greater emotional and bodily expressivity of women's lives - which are linked with the processes of reproduction - could lead them to understand 'body touch' as something less problematic than men (Twigg, 1999). Women have, nevertheless, been found to show a 'gendered sensitivity' of caring for a relative due to their previous experience of taking responsibility towards the care of their elderly/dying relatives (Chatoo and Ahmad, 2008). This indeed has led them to express the wish that their children 'feel free of any potential responsibility towards their personal care' (ibid: 557).

The sexual and gendered meanings of the body have been found to influence elderly/dying people's preference to be cared for by a stranger rather than their adult children. Nurses and care workers are those who are culturally allowed to deal with the body and its wastes and are expected to behave in a manner which provides comfort and emotional support to the sufferer (Twigg, 2000: 74). The provision of intimate care might call into question one's sense of dignity as it involves the exposure and public visibility of the body (Calnan et al., 2006; Chochinov et al., 2002a; Franklin et al., 2006;

Tadd, 2006) and thereby there is the need that these tasks are done in a friendly and supportive environment where patients feel at ease (Hunt, 1991; Rodriquez, 2011). The preference for a hospice death could to a certain extent be related to how hospice professionals care for the unbounded dying body (Gott et al., 2004; Seymour et al., 2007b).

The hospice through its ideal of person-centred holistic care (McNamara, 2004) may be able to enhance patients' sense of dignity and thereby their sense of value as a person with limited bodily capacities (Enes, 2003; Jacelon et al., 2004). The discourse that a death at home is one of the key factors in the achievement of a death with dignity (Seymour et al., 2007b), or what has commonly been called a good death, is thus challenged in light of the above arguments. Indeed hospice care in idealised terms has become synonymous with the good death and therefore it is understandable why dying people and their family may prefer this type of care at the time of dying (ibid). Furthermore, the revivalistic discourse on death (Walter, 1994), which calls for an open awareness and acknowledgement of dying, personal choice and emotional accompaniment of the dying (Seale, 1998), have been found to be at the heart of the preferences for hospice/palliative care (Seymour et al., 2007). It is to a more detailed consideration of these points that I now turn.

2.4.3. The care of the self and the revivalist good death

Walter (1994) argued that there had been a revival of death from its hidden place in hospitals and its denial in public discourses. The revival discourse on death - which arose in contrast to the discourse of modern medicine that instigated the medicalization of dying (Long, 2004) - offered dying people and their families an opportunity to transform symbolically the experience of death into an affirmation of life (Seale, 1998: 5-6). The development of the revivalist discourse on death emerged hand in hand with the growth of the modern hospice and palliative care movement - which called for a more natural way of dying and thereby was seen as a way of rejecting institutionalized forms of dying (Howarth, 2008). The proponents of the movement argued that death had been removed from home and had been located in hospitals (Áries, 1981; Shilling, 1993) which have contributed to the isolation of the dying (Elias, 1985; Armstrong, 1987) who were subject to a number of indignities (Howarth, 2008) in an attempt by doctors to keep them alive (Kellehear, 1984; Walter, 1991). They appealed for a return of death to the realm of individual as well as familial control (Kubler-Ross, 1975) and, therefore, understood the patient and their family as the unit of care (Froggat, 1997).

The revival good death described by the founders of the hospice and palliative care movement thus involved a 'pain free death; death at home, surrounded by family and friends; death as personal growth; death according to personal experience; an aware death, in which personal conflicts and unfinished business are resolved; and open acknowledgment of the imminence of death;' (Clark, 2002: 907). These latter points have led to the adoption of what Glaser and Strauss (1965) have called an open awareness context. An open awareness refers to a context within which the patient, their

family and health care professionals are aware of impending potential death and act accordingly. A closed awareness in contrast refers to a context within which the patient does not know about his/her impending death even though everyone else is aware of it. In between are the context of suspected awareness - where the patient suspects his/her impending potential death - and the context of mutual pretense - where the patient, family and health care professionals have knowledge of impending potential death but pretend that they do not know about it.

Withholding information from those who are dying was understood by the proponents of the modern hospice and palliative care movement as an impediment to a patient's autonomy (Field and James, 1993). An open awareness of dying is believed to offer opportunities for emotional closeness for dying patients and their family (Seale, 1995). A major reward for an awareness of death for patients and their family has been found to be the affirmation of love through intimate talk - which involves the negotiation of intimacy, commitment and mutual trust as well as the re-affirming and re-establishing of a shared history (ibid: 608). As Seale (2004: 967) pointed out: 'confessional deaths, in which terminally ill people fight, face and eventually accept their deaths, reconciling themselves with their loved ones, retelling and sometimes reconstructing personal biographies (...) have become increasingly valued.' The preference for an aware death is a reflection of the individualism which characterises Anglo-American culture (Seale, 1998). The affirmation of the project of the self through awareness of death indeed is a necessary achievement when religious and other traditional narratives no longer sustain the individual (Seale, 1995: 606).

This revivalist discourse on dying which calls for an open awareness might nevertheless not be appropriate in 'cultures where care of the self is more readily given to others, where there is a willingness to trust in authority and respect tradition, and there remains a degree of formal religious influence in explaining existential problems' (Seale, 1998: 111). This is the case, for example, in Japanese culture where there is a high degree of trust in medical authority. Thus Japanese patients are less likely than their American counterparts to see the decisions on end of life in terms of individual choices (Long and Long, 2004). The care of the self within Japanese culture - unlike what happens in Anglo-American culture - is given over to others, namely to the family. Indeed the family in Japan is placed in the position of an intermediary between the medical and the patient's world and thereby doctors tend to disclose the terminal diagnosis to the family first. Within Japanese culture the disclosure of a terminal diagnosis is viewed as an unnecessary cruelty and as a result the family tries to avoid it in the patient's best interest. The family supports the dying patient by reassuring him/her that s/he will recover. There is a fear that by being aware of their terminal diagnosis patients will lose hope and thus will stop fighting to survive - in a most extreme form that they will commit suicide (Long and Long, 1982).

This so-called 'conspiracy of silence' has also become apparent in countries from the South of Europe, namely Italy, Spain and Portugal (Gordon and Paci, 2001; Gonçalves and Castro, 2001; Centeno-Cortes and Núñez-Olarte, 1994), where instead of being interpreted as an act of abandonment or denial it is understood as an act of love and support as the burden of knowledge is taken on the shoulders of family and thereby it protects the patient from suffering (Seale, 1998). For example, Gordon and Paci (2001)

in their study of the traditional practices of concealment and silence around cancer in Tuscany - Italy - found that hope was central for patients' wish to continue living. Hope was built upon reassurance, vagueness and openness and thus created a space for the possibility of a positive outcome. The non-disclosure of a terminal diagnosis was seen by the family as a moral duty as it helps to support the dying patient and avoids his/her social death.

Evidence from Anglophone culture suggests that there is also a degree of resistance to the dominant discourse of an aware death, namely from lay individuals who have questioned its benefits (Seale, 1995). Gott et al. (2008), for example, in their study conducted in the UK on older people's views of a good death in heart failure, found that denial was an important coping strategy in managing the day-to-day realities of living with a life-threatening illness. This is to a certain extent reminiscent of Bury's (1991) notion of normalisation as a form of coping - which refers to 'the psychological bracketing off of the impact of the illness, so that its effects on the person's identity remain relatively slight' (ibid: 460). There is indeed a confirmation from the literature on chronic illness that patients' awareness of their status as terminally ill negatively affects their sense of self as well as their relationships with significant others. Thus, patients might avoid discussing their terminal diagnosis as a way to protect themselves (Exley and Letherby, 2001). The refusal of discussing a terminal diagnosis could also be due to the perception of the consequences that their death might have on their loved ones (McZenzie and Crouch, 2004; Payne et al, 1996b).

What clearly became evident is that a revivalist good death may not be suitable for all dying people as they may not want an open awareness of dying and thereby the

acknowledgment of an imminent potential death (Gott et al., 2008). This may be very much related to cultural factors as well as to personal circumstances. The body of work presented alongside this section has been very important in showing the role of family in the (non) disclosure of a terminal diagnosis and the way in which it might shape the discourse of a revivalist good death. I now turn to a more detailed consideration of the family at end of life.

2.4.4. Family dynamics at end of life: Recognizing cultural diversity

The family is actively involved in the discourse of a revivalist good death proposed by the founders of the modern hospice and palliative care movement. Indeed as Kissane and Block (2002: 1) pointed out, ‘achieving the good death, depends substantially on the family’s competence in offering support, facilitating preparation for dying and affirming the patient’s dignity, as well as saying farewell’. Hospice and palliative care understands the dying person as an integrated whole, a social being with previously established social relations, and thereby, the family along with the dying person is seen as the unit of care (Froggat, 1997: 130). The end of life could be a challenging and difficult period for families where tensions and struggles may come to the fore which thereby may compromise the ideal of family accompaniment (Broom and Kirby, 2013; Lawton, 2000).

The problematic side of family relations at end of life has been shown by Broom and Kirby’s (2013) in their study carried out in an Australian hospice by capturing the strains and difficulties some families experienced at the point of dying. These authors

concluded that relations at end of life are not necessarily positive and affirming. Indeed Broom and Kirby (ibid) found that a lack of family support and an absence of physical presence were common in the hospice. Even in circumstances where the family was supportive at the time of admission into the hospice their presence diminished as the dying process progressed. In addition to outside pressures such as work, mortgages and geographical mobility which limited the capacity of the family to be present at the time of dying and the weeks before this event take place, Broom and Kirby (ibid: 507) noted that families may have such ongoing tensions that communication and interaction between their members becomes impossible.

Broom and Kirby's (2013) findings echoed those of Lawton's (2000) study. Lawton, in her study with British hospice patients, found that these patients were often left alone by family and friends along the dying process and thereby experienced a sense of isolation and alienation. Lawton (2000) further argued that the withdrawal from social and reciprocity networks experienced by hospice patients was deeply interwoven with the processes of individualization (Beck and Beck-Gernsheim, 2001) characteristic of modern western society. This means that an individual's biography is no longer characterized by traditions/obligations but by choices (ibid; Broom and Kirby, 2013: 510). As one's relationship with others exists solely for the rewards that such relationship can deliver (Giddens, 1991: 6), one may feel compelled to withdraw contact from those who are dying as no rewards are made available within such a relationship.

There is nevertheless evidence to suggest that, despite the increasing processes of individualization, individuals continue to invest and to feel embedded in close personal relationships (Gross, 2005; Jamieson, 1999; Mason, 2004; Smart and Shipman, 2004;

Smart, 2007). I thus claim that a more nuanced understanding of relationships at end of life is needed. The withdrawal from contact with hospice patients by family and friends could to a certain extent be explained by the individualistic character of Anglophone culture. Tomassini et al. (2007), for example, found that in a country like the UK where relations between kin are strongly influenced by individualistic values and characteristics support in later life is primarily related to need. This means that family support is activated in accordance with the older person's needs. This could to a certain extent explain why families in both the UK and Australia were supportive of patients with a life-threatening or terminal illness who needed home care assistance including intimate care (Armstrong-Coster, 2004; Ellis, 2010; Thomas et al., 2002; Ussher et al., 2013). With admission into the hospice, families may feel that their support is no longer needed and thereby their interaction with their dying relatives may diminish.

One may question if this is likely to happen in countries with a strong familistic culture such as those from the South of Europe (Andreotti et al., 2001; Dalla Zuanna, 2001; Dykstra and Fokkema, 2010; Jurado-Guerrero and Naldini, 1996; Karamessini, 2008; Lopes, 2006; Moreno, 2006; Reher, 1998; Tavora, 2012). In their study on informal support, Tomassini et al. (2007) found that, unlike what tends to happen in the UK, in Italy support is provided regardless of the older person's individual characteristics. The spirit of a familistic oriented society draws on the assumption that people through their lives seek their own happiness and that of their nuclear family (Dalla Zuanna, 2001: 139). This means that familism cannot cohabit with an excessive individualism (ibid: 154), albeit it can persist even where traditional family- life declines (ibid: 140). There is enough evidence that suggests that in Southern European countries, like Portugal,

individualization and pluralisation of families are not incompatible with the significance of family relationships and support (Aboim et al., 2013: 48).

Despite the recognized importance of families to the character and quality of palliative care (Grande et al., 2009; Harding and Hiddinson, 2003; Hudson et al., 2004; Hudson and Payne, 2011), few studies have explored the family dynamics at end of life (Broom and Kirby, 2013; Kramer et al., 2006; Winter and Parks, 2008). Further research is thus needed to understand interactions between kin and the support they offer within a palliative care environment, in particular in countries with a strong familistic culture such as those from the South of Europe. I will provide an overview of the family dynamics at end of life in Portugal in Chapter Seven, where I analyze the support offered by the family to terminally ill patients and how this might help to prevent their social death.

2.4.5. Bodily autonomy, personhood and dignity at end of life

Having outlined the importance of recognizing cultural diversity amongst family support at end of life, I might doubt the applicability of Lawton's (2000) theory of the relationship between bodily autonomy and personhood/selfhood to non-Anglophone countries. Lawton argued that the loss of bodily autonomy experienced by hospice patients lead to a debasement of their selfhood as it contradicted the ideal of the pursuit of individual freedom which is the hallmark of personhood in modern western society (Hockey and James, 1993). Lawton's arguments appear to be based on the individualistic values which characterized the society within which their study was

conducted. Thus I question whether in societies characterized by strong familistic values personhood is very much related to an individual's autonomy and accountability for their own actions (La Fontaine, 1985). For example, Kitwood's (1997) notion of personhood which describes it as 'a standing or a status that is bestowed upon a human being, by others, in the context of relationship and social being' (ibid: 8) might be more suited to the realities of these countries as it does not place importance on individual characteristics per se but on relationships, whether of a familial or non-familial nature.

Kitwood's (ibid) notion of personhood draws attention to the fact that personhood is essentially social. This means that personhood is 'provided or guaranteed by the presence of others' (Kitwood and Bredin, 1992: 275). For Kitwood 'each person has an absolute value' and thus we 'have an obligation to treat each other with deep respect' (1997: 8). Kitwood's theory draws upon symbolic interactionism and thereby the self is closely tied to social interaction (Kontos, 2003: 158). Lawton's (2000) argument that hospice patients are likely to experience a loss of personhood as a consequence of their loss of bodily autonomy appears in this light to be overly simplistic as no one can lose his or her personhood based on bodily capacities, namely on one's ability to exercise agency. It is rather the treatment provided by others that can damage one's sense of personhood (Kitwood, 1997). Drawing upon Kitwood's work, it could be argued that it is the processes and interactions that depersonalise and invalidate those who are dying and thereby have suffered severe bodily losses that might lead to the loss of a sense of personhood.

As the philosophy and practice of palliative care has been built upon the notion of basic dignity, which refers to the inherent value of human beings (Jacobson, 2007;

Nordenfelt, 2004, 2009), and thereby suggests that for human dignity to be maintained there is the need to understand dying patients as whole persons (Chochinov, 2006), one might question Lawton's (2000) argument that dignity might not be something that patients at the end of life can realistically hope for. Dignity in Lawton's (ibid) study draws some parallels with Nordenfelt's (2004) notion of personal dignity - or what has also been called dignity of identity - which refers to the dignity that individuals have as integrated and autonomous persons. While hospice patients might understand dying and associated biological changes as something undignified (Chochinov, 2006; Elliot and Olver, 2008), palliative care might be able to treat them with respect for who they are as a person and restore their human dignity (Enes, 2003). There is a need to clarify the meaning of dignity at end of life (Sandman, 2002). I will do this in Chapter Six, where I examine the indignities experienced by terminally ill patients and how palliative care might be able to restore or maintain their dignity and sense of personhood in the face of dying and its bodily realities.

2.5. Conclusion

This chapter presented a selected review of literature relating to the bodily realities of illness, ageing and dying. I thereby aimed to provide a theoretical framework for answering the main research question of the current study: *Is the sense of self and identity of terminally ill patients affected by the process of bodily deterioration and decay prior impending potential death? If it is affected, how and why?* Studies on chronic illness have helped us to comprehend that the illness might alter one's body in terms of its ability to function as well as its appearance. A visibly altered body might have a detrimental impact on one's sense of self and identity. Research on dying bodies has nevertheless downplayed this issue. Thus a key question of the study is: *To what extent does a visibly altered body affect the sense of self and identity of terminally ill patients?* Another important aspect that has previously garnered little empirical attention is related to the impact that the loss of bodily capacity has on one's sense of self and identity. There is a need for further insight into the experience of loss of bodily autonomy at end of life. Findings so far have not properly acknowledged bodily diversity. Hence another key question is: *In what ways does the loss of bodily autonomy affect the sense of self and identity of terminally ill patients?* Studies within the sociology of chronic illness and ageing have shown that men and women are likely to experience their bodies differently. Gender differences might have implications on how terminally ill patients experience a visibly altered body and a physically changed body. Attention will thus be paid to gender differences whenever appropriate.

Studies within the sociology of dying have suggested that the bodily losses experienced by dying patients threaten their sense of dignity and thereby their personhood. This

limited research nevertheless draws upon individualistic assumptions which related personhood and dignity with bodily autonomy. There is a need to challenge such conceptions. Based on holistic notions of personhood and dignity I question if *in the light of the bodily realities of dying, a dignified death is something that hospice patients can realistically hope for?* Insights from the sociology of dying also suggest that the discourse of a lonely death and its avoidance instigated by the founders of the modern hospice and palliative care movement have been challenged by individualization processes which have led to the abandonment of dying people in hospices. The processes of interactionality at end of life have nevertheless received inadequate attention. Thus the ways in which the family might prevent a lonely death will be investigated in this study: *Are terminally ill patients likely to experience a social death prior to their physical cessation?* The sociology of dying also showed that the dying experience is profoundly marked by cultural differences and therefore there is the need to recognize this with respect to the dying process. Most of the studies on dying and its bodily realities have been conducted in countries with an individualistic nature such as England and Australia and thereby their conclusions are situated rather than able to be generalized. Further research is needed in countries with a familistic nature such as Portugal to provide novel insights into the embodied experience of living and dying in a hospice. The research questions that will be explored in the current study will be outlined next.

2.5.1. The research questions

The main research questions that guided the current study are:

- Is the sense of self and identity of terminally ill patients in Portugal affected by the process of bodily deterioration and decay prior to impending potential death? If it is affected, how and why?

Along with this, the current study aims to answer to the following subsidiary questions:

- To what extent does a visibly altered body affect the sense of self and identity of terminally ill patients? Does it differ by gender?
- In what ways does the loss of bodily autonomy affect the sense of self and identity of terminally ill patients? Does it differ by gender?
- In the light of the bodily realities of dying is a dignified death something that Portuguese terminally ill patients can realistically hope for?
- Are terminally ill patients in Portugal likely to experience a social death prior to their physical cessation?

The methodology used to answer these research questions will be presented in Chapter Three.

Chapter Three

Methodological issues

3.1. Introduction

This chapter is concerned with the methodological aspects of the current study. A qualitative research strategy was adopted to answer the research questions arising from the literature review as it offered an opportunity to explore the living experience of those who are dying, as well as of those who accompanied and cared for them at the time of dying. As the study involved direct contact with a particularly vulnerable group, terminally ill patients, whose interests cannot be easily protected (Addington-Hall, 2007) qualitative research methods appeared to be most appropriate for studying the experiences of these subjects, as they are flexible and fluid (Liamputtong, 2007). The term vulnerable has been applied to people who experience ‘diminished autonomy due to physiological/psychological factors or status inequalities’ (Silva, 1995: 15). This has been extended to people ‘who lack the ability to make personal life choices, to make personal decisions, to maintain independence, and not to self-determine’ (Moore and Miller, 1999: 1034).

The chapter is divided into seven sections. The first section describes the research approach. The methods of data collection - participant observation and in-depth interviews - are outlined here. The sample of this study is highlighted in the second section. The third section illuminates the ethical aspects of the study. Ethical issues around the giving of information, risks and benefits of participation, and the right to anonymity, privacy and confidentiality require particular attention when conducting

research with a vulnerable population. The process of gaining ethical approval for the study is also described. The outline of the research context is presented in the fourth section. The emotional nature of the research is analysed in the fifth section. The process of analysing the data by taking into account a grounded theory approach is examined in the sixth section. The final section discusses the plausibility and generalisability of the study.

3.2. The research design

As a method, ethnography was originally developed by anthropologists as a means to gaining an in-depth understanding of other cultures (Hesse-Biber and Leavy, 2005), and it was soon adopted by sociologists to describe specific social settings (Delamont, 2004) and to capture the meanings attributed by individuals to their own experiences (Fielding, 2008). ‘The ethnographic method provides the researcher with an important window into understanding the social world from the vantage point of view of those residing in it’ (Hesse-Biber and Leavy, 2005: 269). Ethnography has been one of the most widely used methods of data collection within the field of sociology, and in particular medical sociology (Chamaz and Oleson, 2007). ‘A great deal of our knowledge about palliative care, especially in relation to the experience of pain and suffering, understanding of death and dying, and the process of organization of clinical care, communication and interaction stems from a relatively small collection of ethnographic studies’ (Seymour, 2007: 211).

Within the tradition of the ethnographic method, participant observation has been key to the process of data collection as it enables researchers to provide ‘thick descriptions’ of the social world within which the research is being developed and the individuals who inhabit such world (Hesser-Biber and Leavy, 2005: 270). Participant observation provided a viable means of gaining insight into the experiences of terminally ill patients, as well as those of their family and caring professionals. As participant observation is a non-invasive and unobtrusive method of data collection it provides me with an opportunity to spend a considerable amount of time with participants without making extra demands on their time and emotional situation (Lawton, 2001; Liamputtong, 2007). My observational range was limited to events that took place in two palliative care units for cancer and non-cancer patients located in Lisbon, the capital of Portugal. This setting was chosen because it has been found to be the place - in a study previously conducted by Lawton (2000) - where the process of bodily deterioration and decay became visible in a sharp form.

Participant observation was complemented by in-depth interviews in order to gain a great depth of information and knowledge from research participants (Johnson, 2002). The understanding of a specific social world is obtained through verbal messages (Hesse-Biber and Leavy, 2005). The in-depth interviewing method has been found to be ‘more preferable amongst sensitive researchers who wish to be close to their participants in order to allow them to speak about their lived world in greater depth’ (Liamputtong, 2007: 96-97). Through the use of in-depth interviews I was able to capture the views and experiences of terminally ill patients, their family and caring professionals on a number of topics related to dying and its bodily realities. This offered

me valuable insights into how and why the sense of self and identity of terminally ill patients are affected by the process of bodily deterioration and decay prior to impending potential death.

Having outlined the research design, the next section will provide a detailed discussion about the sample of this study.

3.3. The research sample

The research sample of the current study consisted of a total of 50 participants. Initially I intended to interview and observe 20 terminally ill patients. However during the course of the fieldwork it soon became evident that the recruitment of terminally ill patients would be very difficult. As fewer patients due to their debilitating and deteriorating condition were able to take part in the study I decreased their number in the sample to ten. The sample was not numerically representative of the whole population of terminally ill patients but, instead, it enabled me to identify a range of experiences. The number of patients might at a first sight appear to be small but it should be taken into consideration that such sample size ‘enhanced the validity of fine-grained, in-depth inquiry’ (Crouch and McZenzie, 2000: 183). This also helped me to ‘link individual experience to existing theory and conceptual frameworks, knowledge of the social circumstances in which participants were contextually located’ (Lan and van Niekerk, 2011: 1168).

I decided that patients who were mentally confused, unable to express themselves or were too unwell to permit data collection would not take part in the study as it could

compromise data validity (Payne et al., 1996). This information was checked with the staff, namely with nurses. Patients also needed to be in palliative care for more than 48 hours so their clinical condition could be somehow ‘stable’. I approached patients in their room and asked them if they would like to take part in the study. Seven patients refused by saying that they did not want to talk about their illness or were not feeling well enough to be interviewed. All the patients who agreed to take part suffered from cancer and were aged between 45 and 80-years-old. The interviews were conducted at each patient’s bedside after obtaining their formal consent. No one except the patient and I were present at the time of the interviews. I tried to achieve a reasonable balance and representation by sex. Five men and five women agreed to reflect on their deteriorating and debilitating bodily experiences. The characteristics of these patients are presented in table 1.

Table 1 – Characteristics of Patients

Patient ID	Pseudonym	Gender	Age	Diagnosis	Length of time in the unit at interview
P1	Brian	Male	45	Colon Cancer	7 months
P2	Brenda	Female	65	Merkel Cell Carcinoma	3 weeks
P3	Brad	Male	58	Prostate Cancer	1 month
P4	Beatrice	Female	68	Occult Tumor	1 month
P5	Bella	Female	72	Ovarian Cancer	10 days
P6	Ben	Male	52	Esophageal Cancer	10 days
P7	Bob	Male	59	Liver Cancer	5 days
P8	Billy	Male	78	Lung Cancer	3 days
P9	Becky	Female	78	Ovary Cancer	14 days
P10	Bridget	Female	69	Esophageal Cancer	4 days

Proxies (i.e. family members) were also a vital source of information about patients' processes of dying and their bodily experiences. This enabled that the experiences of patients who were not able and willing to participate could be integrated into the study and thereby avoided a potential bias. The review conducted by McPherson and Addington-Hall (2003) provided evidence that encourages the use of proxies at end of life. The authors convincingly demonstrated that, 'studies relying on patients' accounts prior to death are potentially biased, as they only represent the proportion of patients with an identifiable terminal illness, who are relatively well and therefore able to participate, and who are willing to take part' (ibid: 95). McPherson and Addington-Hall's review suggested that proxies may be able to view patients' experiences more objectively. This might be particularly true when the patient is tired or confused. Nevertheless, their review indicated that there is a need for caution when analyzing 'aspects of the patient's experiences that are more subjective, such as pain and affective states' (ibid: 106). As it has been found that proxies who had lived and cared for the patient are the best informed and thereby the better able to report on the patient's experiences (ibid) I decided to interview patients' primary caregivers. The observation of the interaction between patients and their family, as well as informal conversations with staff enabled me to identify who was the most appropriate person to act as a proxy. Wives were found to be the most significant person to the patient, followed by daughters and husbands.

After identifying family members as the patient's proxy, these people were approached in the patient's room with the patient's verbal consent. This means that patients - except those who were mentally confused or suffered from cognitive impairment - were aware

of the study and of the participation of their family members. None of the patients were against the participation of their family member - despite some of them having refused to take part themselves. Also, eight family members refused to be interviewed by explaining that they felt emotionally tired and/or wanted to spend time with their loved one. A total of 20 family members expressed their willingness to participate (of these only two had a relationship with patients interviewed: Beatrice and Becky). Although it was my intention to triangulate families' and patients' accounts this was in the majority of cases not possible due to the reasons mentioned previously. Interviews with family members were conducted in a private area of the in-patient unit, namely in the living room or in the cafeteria after obtaining their formal consent. The characteristics of family members are presented in table 2. As shown in this table, most were female and aged between 41 to 78 years old.

Table 2 – Characteristics of Family Members

Family Member ID	Pseudo-nym	Age	Gender	Relation	Patient's age	Patient's gender	Patient's diagnosis	Patient's length of time in unit at interview
F1	Abby	58	Female	Wife	58	Male	Lung Cancer	2 months
F2	Anna	55	Female	Daughter	77	Female	Spongiform Encephalopathy	5 months
FE	Alvin	75	Male	Husband	70	Female	Multiple Myeloma	5 months
F4	Alan	76	Male	Husband	80	Female	Non Hodgkin's Lymphoma	3 months
F5	Addison	56	Female	Wife	58	Male	Colon Cancer	1 month
F6	Adriana	73	Female	Wife	82	Male	Vegetative State	3 months
F7	Alice	59	Female	Wife	63	Male	Esophageal Cancer	12 months
F8	Andie	71	Male	Wife	62	Female	Malignant Glioma	4 months
F9	Alicia	71	Female	Cousin	77	Female	Colon Cancer	7 months
F10	Amelia	61	Female	Daughter	96	Female	Vegetative State	14 months
F11	Anastasia	64	Female	Wife	69	Male	Prostate Cancer	4 months
F12	Adele	46	Female	Daughter	87	Male	Bladder Cancer	25 days
F13	Albert	66	Male	Husband	67	Female	Occult Tumor	1 month
F14	Aaron	59	Male	Son	85	Female	Rectal Cancer	1 week
F15	Alphonso	45	Male	Son	71	Female	Chordoma	1 month
F16	Amanda	40	Female	Daughter	66	Female	Tongue Cancer	3 weeks
F17	Angela	78	Female	Sister-in-law	78	Female	Ovary Cancer	14 days
F18	Antonia	60	Female	Wife	66	Male	Brain Cancer	4 days
F19	Andrea	65	Female	Wife	72	Male	Lung Cancer	4 days
F20	April	41	Female	Daughter	64	Female	Breast Cancer	5 days

The accounts of palliative care professionals provided a basis of triangulation with patients' and family members' accounts of dying and its bodily realities. This offered a multidimensional picture of the phenomena being investigated (McDonnell et al. 2000). I then decided to interview 20 staff members. I approached palliative care professionals in the staff room and asked them if they would like to be interviewed for research purposes. Of the 21 approached 20 accepted. One nurse did not agree to take part in the study as she was too busy. However when I tried to schedule the interview when she had more time she refused to do so. I intended to achieve a reasonable balance and representation between the different professional categories, and thereby doctors, nurses, therapists, psychologists, social workers, volunteers and spiritual and religious counselors were invited to participate in the study. Interviews with palliative care professionals were conducted in a private area of the in-patient unit, namely in the living room or in the cafeteria after I obtained formal consent. The 20 palliative care professionals interviewed for the study had direct contact with the patients and family members interviewed - albeit no mention was made of specific patients or family members during the interview. The characteristics of palliative care professionals are presented in table 3. Most were women and aged between 23 and 64 years old.

Table 3 – Characteristics of Palliative Care Professionals

Staff ID	Pseudo-nym	Age	Gender	Occupational Category	Time worked in the unit	Prior experience with seriously ill patients	Formal training in palliative care
C1	Chloe	30	Female	Nurse	4 years (since its opening)	Yes	Yes
C2	Chris	31	Female	Physiotherapist	4 years (since its opening)	No	Yes
C3	Cameron	38	Female	Occupational Therapist	4 years (since its opening)	No	Yes
C4	Candy	33	Female	Psychologist	4 years (since its opening)	No	Yes
C5	Clarice	26	Female	Psycho-social Therapist	2 years	No	Yes
C6	Clara	28	Female	Nurse	10 months	No	No
C7	Carla	26	Female	Nurse	4 years (since its opening)	Yes	Yes
C8	Charlie	39	Male	Spiritual & Religious Counsellor	2 years	Yes	Yes
C9	Charlotte	44	Female	Chief-Nurse	4 years (since its opening)	Yes	Yes
C10	Carmen	49	Female	Doctor	4 years (since its opening)	Yes	Yes
C11	Capri	48	Female	Spiritual & Religious Counsellor	4 years (since its opening)	No	Yes
C12	Catherine	35	Female	Physiotherapist	4 years (since its opening)	No	No
C13	Chandler	64	Male	Volunteer	3 years	Yes	Yes
C14	Cecilia	29	Female	Nurse	4 years (since its opening)	Yes	No
C15	Carl	23	Male	Nurse	2 years	Yes	No
C16	Celeste	38	Female	Social Worker	4 years (since its opening)	Yes	No
C17	Chantal	30	Female	Psychologist	4 years (since its opening)	Yes	Yes
C18	Ciara	43	Female	Chief-Nurse	4 years (since its opening)	Yes	Yes
C19	Castle	38	Male	Doctor	4 years (since its opening)	Yes	Yes
C20	Claire	31	Female	Nurse	4 years (since its opening)	Yes	No

The cases were not selected on the basis of representativeness but for their illustrative nature (McDonnell et al., 2000).

The present section has discussed the sample of this study; the ethical aspects will be highlighted in the next section.

3.4. Ethical issues

Here I consider the ethical aspects that have informed the current study. First it is important to highlight that attempts to investigate the bodily realities of the dying raise some ethical challenges related to the ways in which the study is introduced and explained to terminally ill patients (Entwistle et al., 2002; Ryen, 2004). Concerns have been raised about the vulnerability of terminally ill patients, especially their impaired decision-making capacity and their need for special ethical protection when participating in research (Addington-Hall, 2002; Lawton, 2001; Hewitt, 2007; Moore and Miller, 1999; Tee and Lathlean, 2004; Smith, 2007). The ‘Nuremberg Code’ in 1949 was the first international code of ethics established as a means to protect the rights of individuals from research abuse (Liamputtong, 2007: 24). This was followed in 1979 by the ‘Belmont Report’ which outlined the centrality of respect for individuals, beneficence and justice. These principals inspired the creation of other ethical frameworks in western society (Christians, 2000).

Within the domain of sociological research, each national association has its own code of ethical practice (São José and Teixeira, 2013). As the study was carried out in Portugal, it made sense that I used the code of ethical practice of the Portuguese

Sociological Association. The code calls for guarantees of confidentiality, anonymity and avoidance of harm. However concerning informed consent the code is not clear about the term albeit it was mentioned that ‘sociologists should not violate the principals of willingness of providing information by individuals, populations and institutions’ (APS, 1992: 8).

Unlike the ‘sciences of life’, the social sciences in Portugal are not expected to satisfy any special ethical requirement. There is no national council for social science research in this country. In contrast, there are two councils concerned with health issues: the National Medical Ethics and Deontology Council and the National Ethics Council for ‘Life Sciences’. The former, as a medical body, refers to problems which arise during medical practice, while the later is concerned with analyzing the moral problems which arise from scientific progress in the fields of biology, medicine or general health care. These councils only gave their opinion on subjects related to clinical research. Also, the Portuguese Law Number 97/94 of 9 April 1994 regarding clinical studies of human subjects is so far only concerned with pharmacological research.

The Portuguese Law Number 97/95 of 10 May 1995 regulated the establishment of Health Ethical Committees in Public and Private Health Care Institutions. These Health Ethical Committees were only concerned with regulating clinical research and are mainly based in Primary Hospitals. Unlike the educational and research organizations in the domain of ‘Life Sciences’, there is no tradition of Research Ethics Committee at this type of organization with respect to Social Sciences in Portugal (São José and Teixeira, 2013). This was so in the Center for Research and Studies in Sociology, my host research center in Portugal. The Portuguese Foundation of Science and Technology, the

agency which financially supported my study, and the largest agency for funding research in Portugal, did not have a code of ethical practice in the domain of the Social Sciences (ibid). Thus, there was no need to require official ethical approval in the country where the study was conducted.

An ethics form was nevertheless sent for approval to the Research Ethics Committee of Royal Holloway-University of London, my host university. This process was very time consuming as approval was only granted after five months of submission (Appendix 1). A requirement for approval from the Research Ethics Committee of Royal Holloway-University of London was that terminally ill patients needed to give written consent for observation of daily activities. An agreement was made that when terminally ill patients were not able to give their written consent due to their process of bodily deterioration and decay, family members were able to act as proxies (Appendix 2). The ethical guidelines offered by the Statement of Ethical Practice of the British Sociological Association (2002) were taken into consideration. Attention was particularly paid to issues of informed consent and overt research. The British Sociological Association is not in favour of covert research and their code states that: 'covert methods violate the principles of informed consent and may invade the privacy of those being studied' (BSA, 2002: 4).

In order to access the research sites, a formal letter was sent to the clinical director of the in-patient unit 1 and to the chief-nurse of the in-patient unit 2 explaining the study and inviting them to discuss any concerns they might have in a formal meeting. The ethical safeguards specified were satisfactory for both the clinical director and the chief-nurse and they gave permission for the research to be conducted. As both facilities were

private there was no need to require permission from the Portuguese State's Health Authority. Also, a Research Ethics Committee did not exist in these sites. The clinical director of in-patient unit 1 and the chief-nurse of in-patient unit 2 gave their verbal consent for observation of the communal areas of the units as well as of patient's private facilities - namely their rooms. I was nevertheless not allowed to be present during intimate care (e.g. bathing and the change of a diaper) as a means to protect patient's privacy. Verbal consent was also obtained from staff for the observation of nursing handovers and team meetings.

Written consent for observation was obtained from terminally ill patients or their family members (Appendix 3 and 4). Written consent limited my observational range to certain events as it took place after the interview was conducted with them. I believed that the trust between me and participants would increase after the interview (Stalker, 1998) and that this would minimize their 'reactivity' to the researcher (Hammerley, 2003). Participants were informed that the recording of observational data would take place in the form of field notes in a fieldwork diary (Appendix 5 and 6). Even though participants had given their formal consent for observational purposes this could not be taken-for-granted in subsequent encounters with them (Lawton, 2001: 699). Thus, I constantly had to remind participants about my role as a researcher in my interaction with them. The use of a badge with my name and institutional affiliation appeared to help. I decided not to take the role of a volunteer - unlike researchers in previous studies conducted with hospice patients (e.g. Lawton, 2000; Ellis, 2001) - as this could be tricky as participants could interact with me first and foremost in my role as volunteer and thus the validity of my data could be compromised (Lawton, 2001: 699). In addition

to the protocol established, and like Ellis I used my 'own moral and emotional sensibilities to read situations and responses', and 'took certain practical observational decisions based on this as well' (2010: 130). As Guillemin and Gilliam (2004) outlined, there are a number of everyday difficulties which emerge in the course of the research that cannot be anticipated. A reflexive approach has helped me to overcome these practical difficulties.

A requirement for interviewing terminally ill patients, family members and palliative care professionals was that written consent was given by respondents after they had been informed in writing about the aims, methods, benefits, and risks of the study (Richards and Schwartz, 2002; Seymour and Skilbeck, 2002). An important point to be made here is that the process of asking written consent from research participants appeared to be odd for most of them - with the exception of palliative care staff who were familiarised with written consent. This was related with the nature of Portuguese society as 'signing a contract means that the issue in question is serious and that breaking of duties can lead to severe consequences for the parties involved' (São José and Teixeira, 2013: 56). As outlined by São José and Teixeira, in Portuguese society 'it is not typical for a person to sign a contract with a domestic employer in order to obtain domestic services from her/him' (ibid: 56). The initial apprehension/suspicion of participants in signing the consent form waived as soon as I explained to them the importance of written consent and they kindly agreed to sign the consent form. To be sure that they understood their participation in the research, I read the information sheets (Appendix 7, 8 and 9) and the consent form (Appendix 10, 11 and 12) before the interview took place (Fravel and Boss, 1992).

Informed consent was obtained from research participants on the understanding that participation was voluntary (Casarett et al., 2000) and that they could withdraw it at any time (Tee and Lathlean, 2004). I explained to participants that if they did not want to participate in the research study or wanted to withdraw this would not affect their care or the care of their relatives. It was important to explain this to participants as they could to a certain extent feel obligated to participate in the study due to the fear that their care or work would be compromised. Participants were also informed that if they feel uncomfortable or sad during the interview, they were free to ask to stop the interview and specialist counselling would be offered by the psychologist of the unit. None of them asked to do so.

Participants were given the option to use their own names or to use pseudonyms. The use of their own names could be understood as a way to bring meaning to a life event which could otherwise be viewed as meaningless (Wislow et al., 2005). Nevertheless, all participants expressed the desire to use pseudonyms so no one would be able to identify them. I gave them the option of omitting questions that they did not want to answer but, again, this option was not taken. The participants' rights to anonymity, privacy and confidentiality were protected both during and after the fieldwork (Boman and Jevne, 2000; Jorgensen, 1989; Lee and Renzetti, 1993; Ramcharan and Cutcliffe, 2001; Marvasti, 2004). I also ensured that participants felt comfortable with the use of audio taping during the interviews and that they understood the research procedures employed (Wilkie, 2007). Participants were also informed that interviews would be transcribed and coded and were given a copy of the information sheet to keep. Information sheets and consent forms for interview and observation purposes were

translated by me from English to Portuguese since respondents were Portuguese speakers and not English speakers (Appendices 13, 14, 15, 16, 17, 18, 19, 20, 21 and 22). I informed them that a short report would be sent to family members and palliative care professionals informing them of the results after the completion of the PhD thesis.

Having discussed the ethical aspects of the study, I will next describe the research context.

3.5. Outline of the research context

The ethnographic fieldwork was conducted over 10 months in two palliative care units: which will be described here as in-patient unit 1 and in-patient unit 2. The selection of these units was mainly for practical reasons as both were located in the area of Lisbon - a city I live close to in Portugal. The reason why the study was conducted in two different sites was to avoid potential bias as the findings of the study could not be related to a particular context per se - unlike in Lawton's (2000) study. At the time of my fieldwork there were 19 palliative care units in Portugal (Neto et al., 2010). From a total of seven units which were located in the area of Lisbon, only three offered in-patient care to terminally ill people and their families. One refused to take part in the study. The reason given was the fact that all the studies conducted at the unit needed to be supervised by the team psychologist, who at the time was not available for that kind of work. I was quite surprised by such a request, which could compromise the validity of the study. The other two units, which offered in-patient palliative care services in the area of Lisbon, were then contacted and agreed to take part in the study.

I carried out the fieldwork first in the in-patient unit 1, which provided continuous and palliative care to patients on a private basis. Out of a total of 110 beds, 40 were financially supported by the state. Of these 40 beds, only eight were for terminally ill patients. The initial period of ethnographic fieldwork ran from the beginning of March to the end of July 2010. The second period of ethnographic fieldwork, conducted between September 2010 and January 2011, was carried out in the in-patient unit 2. Out of a total of 10 beds for terminally ill patients, eight were financially supported by the state. No distinction was made for the inclusion in the study of patients who were supported by the state from those who were not.

In the in-patient unit 1 a single room was offered to patients on a private basis, whereas the patients who were supported by the state had to share a room with another patient of the same sex. Both private and state funded rooms had private bathroom facilities. In contrast, in the in-patient unit 2 all patients had access to a single room. While those who were admitted on a private basis had private bathroom facilities, those who were supported by the state had to share a bathroom with other patients. Not all the rooms in the in-patient unit 2 had private bathroom facilities. There were no differences in terms of the services offered and the treatment given by the staff to patients who were or were not supported by the state in both in-patient units. The rooms were well furnished with an articulated bed, a bedside table where usually patients displayed photos of themselves and/or their family, a wardrobe, a recliner chair, and a TV. Both the units had a living room with a TV and a dining room where patients could have their meals. However most of them preferred to eat in the privacy of their rooms seated in their reclining chairs or in their beds. I decided not to describe the units in more detail in

order to protect the research sites and their staff. There were only three units which offered in-patient services to palliative care patients and their families in the area of Lisbon, and thereby, it would not be surprising if further information about the research sites led to easy identification of the units and anonymity being seriously compromised.

I experienced more practical difficulties whilst conducting the ethnographic fieldwork in the in-patient unit 1. This was because, contrary to what had happened in in-patient unit 2, I was not permitted by the chief-nurse to observe the nursing handovers and the multidisciplinary team meetings in the in-patient unit 1. The chief-nurse of in-patient unit 1 explained to me that this was so because I was not a member of the palliative care team and only members were allowed to participate in the nursing handovers and team meetings. In the in-patient unit 2, the nursing handovers happened at the end of each shift so nurses could familiarize themselves with the patients' clinical information, whereas the multidisciplinary team meetings were held in the morning at the end of each week and were attended by the principal doctor, the senior nurse, the junior nurse and the psychologist and, occasionally, by the social worker, the volunteer and the religious and spiritual counselor. At each meeting, the team discussed each patient's status in detail and made joint decisions. The information discussed in the nursing handovers and team meetings were annotated by me in my fieldwork diary.

I spent three days per week - five hours per day - with patients, family members and palliative care professionals in the rooms and in the communal areas of both in-patient units. Although both in-patient units were open for visitors between 9am and 9pm family members and friends - as well as myself - were not encouraged to visit patients during the morning in order not to disturb some care routines such as bathing and

dressing. Some family members - namely those family members who were retired - came to the unit at lunch time and spent all afternoon with their loved one. Those who worked or who didn't live nearby came to the unit at the end of the afternoon near dinner time. Most patients had visits on a weekly or daily basis. Although it was possible for family members to stay during the night - they could sleep in a recliner chair in the patient's bedroom - just one had done this. The length of time patients stayed at the unit varied from a couple of weeks to some months or even a year. In accord with staff members of both in-patient units from the time of admission until the moment of dying patients were likely to stay on average a period of three months. Most patients end up dying at the in-patient unit. The staff did not feel any kind of pressure to discharge the patients - in contrast to what happened for instance in Lawton's (2000) study.

Most of the patients who were admitted into both in-patient units suffered from cancer - however a few suffered from other illnesses such as neurological disorders like multiple sclerosis, or were in a vegetative state. The major reasons for why patients were admitted into the in-patient units were for symptom control as well as due to the 'burn-out' of families. Patients could be admitted via the National Health System which was free of charge or apply for a private room, which meant they had to support all costs - a few had private health insurance and thus could be reimbursed. Admission via the National Health System was not controlled by palliative care staff but by Health Care Managers. Priority was given to patients who were in a more difficult condition - whether they were close to death, experiencing extreme suffering or couldn't be cared for at home - and not to those who needed respite care.

Although ideally it would have been beneficial for the study to observe patients and their families alongside all the processes of bodily deterioration and decay prior to impending potential death this was not possible due to time and funding constraints. Also, the unpredictability of illness constrained the observation to particular moments in time (Ellis, 2010). As patients approached death family members tended to spend more time in the palliative care unit. Not surprisingly the relatives with whom I had more contact and who thereby formed the bulk of my observational notes and analysis were the relatives of patients who were in a more debilitating and deteriorating condition. I participated in informal conversations with patients, family members and palliative care professionals. Whenever needed I helped patients with food, brought them water or magazines to read, changed the TV or the radio, and went outside to buy them cigarettes. I also participated in formal meetings referred to as ‘family meetings’ between patients, their relatives and some staff members. My role was more of a listener than a questioner. I observed how these different actors interacted alongside the dying process and the impact that the process of bodily deterioration and decay had on them. Participant observation was organised around a topic guide (Appendix 23), which covered the following issues: a) routines and practices of care; b) patient’s physical autonomy and capacity for bodily control; c) patient’s self-appearance; d) patient’s sense of self; e) patient’s sense of dignity.

The observational data were documented in field notes. These described certain events, actions and interactions in detail and were complemented by a fieldwork diary (Clark, 2001; Emerson et al., 2001; Gilbert, 2008). As participants could feel uncomfortable with the recording of field notes, observational data were recorded in the nursing staff

room of the palliative care facility (Seymour, 2007). In order to make observation manageable, I made condensed notes, which were expanded at the end of each day. Because the data were reconstructed retrospectively, I was not able to collect long quotes from participants (Lawton, 2001). The observational process allowed me to incorporate the behaviors of participants into the analysis of the interview data.

Interviews with terminally ill patients followed a topic guide (Appendix 24), which covered the following issues: a) illness experience; b) routines and practices of care; c) physical autonomy and capacity for bodily control; d) self-appearance; e) sense of self; f) sense of dignity; g) biographical data. Interviews of this kind require that a certain rapport be established between researcher and participant (Stalker, 1998). Before conducting an interview with terminally ill patients, I needed to know the amount of information that they had about their clinical condition, including, in particular, if they knew that they were dying. Interaction with terminally ill patients and conversations with family members and staff helped to clarify this situation. In circumstances where the patient did not know that he/she was terminally ill, I did not disclose the prognosis. Phrases such as ‘bodily deterioration’, ‘terminal illness’, ‘dying process’ and ‘death event’ were never used in interviews.

Interviews with family members and palliative care professionals followed a topic guide (Appendix 25 and Appendix 26), which, with some variations, covered the following issues: a) patient’s illness experience; b) routines and practices of care; c) patient’s physical autonomy and capacity for bodily control; d) patient’s self-appearance; e) patient’s sense of self; f) patient’s sense of dignity; g) biographical data. Using a topic guide, I was able to ask participants specific questions (Jorgensen, 1989). These

questions were as open ended as possible in order to obtain spontaneous information and to encourage participants to communicate honestly about their opinions and ideas (Gilbert, 2008).

3.6. Working with emotions

The present section aims to provide a reflection on the emotional nature of my research. Conducting research on sensitive topics such as dying and its bodily realities may be an emotional experience for both researcher and participant (Hubbard et al., 2001). Emotion has been acknowledged as an important part of human life and it has been recognised that a fundamental aspect of being human is the capacity to feel and show emotion (Gilbert, 2001). Empathic behaviour, both verbal and non-verbal, has been described as the most common strategy used by researchers to minimize the emotional impact that the research experience could have on participants (Ducombe and Jessop, 2002; Hakansson and Montgomery, 2003). In this study, in order to avoid negative feelings on the part of participants during data collection I adopted an empathic approach. Through touch, I eased the emotional distress of participants when they talked about painful or stressful issues. I tried to be as sensitive as possible to the needs and wishes of participants. Listening with concern and compassion and maintaining eye contact with participants were other empathic strategies I employed to prevent negative feelings.

I was highly concerned with participants' emotional reactions to the research (Dickson-Swift et al., 2007). Their most common emotion was uncertainty about the illness, with

the seeking of reassurance dominating theirs and their family members' narratives. This point was also made apparent in Watts' (2008) ethnographic study of a cancer drop-in centre. Watts stressed that the seeking of reassurance by cancer patients was emotionally distressing for her because, despite her reassuring answer, she could not promise patients that they would get better. Feelings of powerlessness and frustration at not being able to help participants, as described by Melrose (2002) in her study about juvenile prostitution, were in a similar way experienced by me. It is worth mentioning that on more than one occasion, I felt some pressure from staff to disclose aspects of the conversation with patients and their family members. Johnson and Clarke (2003) similarly found that researchers experience pressure to report back to the health care professionals responsible for referring patients to their study. The obligation to participants' confidentiality meant that I was not able to disclose information to staff. This was explained to them and they were very understanding.

The broad methodological issues of involvement, detachment and personal responsibility can acquire an added significance when studying topics of an emotive nature (Cannon, 1989). Dickson-Swift et al. (2007) found that the boundaries between researcher and participants could easily become blurred; therefore participants were constantly reminded of the purpose of my relationship. The boundaries in ongoing research relationships are not static and can shift over time due to changing personal circumstances not only of the participant, but also of the researcher (Watts, 2008). Thus, as recommended by Dickson-Swift et al. (2006), I tried not to be emotionally involved with participants and to maintain a certain degree of detachment from the research. This offered me some protection against emotional affectivity during episodes of data

collection (Dickson-Swift et al., 2008a). Also, I decided to leave some space between interviews in order to process any information that could be distressing to me and thus to decrease my risk of burnout.

There is a growing awareness that conducting research on sensitive topics such as the experience of living with a terminal illness may have a profound impact on researchers' wellbeing (Dickson-Swift et al., 2008a; Lalor et al., 2006). Indeed, prolonged contact with the sufferer of a terminal illness may raise personal fears about one's own mortality and that of one's family and friends (Clark et al., 2000; Johnson and Clarke, 2003). This negative emotion led me to ask myself: how would I react if a family member had a terminal illness? How would I react if I had a terminal illness? This proximity of death was difficult for me to deal with and respond to. Watts (2008) similarly experienced this negative emotion when she was confronted with impending potential death in her study of a cancer drop-in facility. Entering an emotionally demanding territory such as end of life care and hearing the voices of terminally ill patients and of those who care for them, involved a considerable amount of emotional labour on my part. I not only had to deal with the respondents' feelings, but at the same time with the feelings aroused in me by their narratives.

To minimize the impact of the proximity of death and the negative emotions associated with it, I employed a number of strategies that helped me to release feelings of distress. Writing a journal about the fieldwork helped me to deal with such emotionally demanding work. As outlined by Rager (2005), peer debriefing with some colleagues provided an opportunity to discuss the cognitive and emotional challenges that I encountered throughout the research process. Also, conversations with family members

and friends were a very important source of support. The regular practice of relaxation techniques such as yoga and reiki also helped me to deal with problematic feelings (Rager, 2005). As described by Dikson-Swift et al. (2008a), I experienced feelings of gratitude and debt to research participants who have shared important aspects of their lives and their deaths. Indeed the research process was very rewarding as I acknowledged that it enabled terminally ill patients and family members to have their voices heard.

The participation in research was found to be very important for patients and their family members as it gave them the opportunity to give something back to society (Terry et al., 2006). The patients and family members said that their agreement to be involved in the study was mainly for altruistic reasons. Although the research did not benefit patients or family members directly, the participants believed that the study could help to improve the care of future patients and their families. The participation in research was emotionally demanding for patients and family members as it encouraged them to think about painful issues but, at one and the same time, it was a cathartic and/or therapeutic experience for them as it provided an opportunity for emotional release.

3.7. The data analysis process

Interviews with terminally ill patients, family members and palliative care professionals were recorded on a digital voice recorder (Olympus VN-6800PC) with the participants' permission and lasted around 40 to 90 minutes. Interviews with patients were on average shorter than interviews with family members and staff. This was because of patients' debilitating and deteriorating condition. A back up tape recorder was also used in case the digital recorder failed. I ensured that participants felt comfortable with the use of an audio recorder. Interviews were conducted in Portuguese and translated verbatim. Typed transcriptions were checked twice with the audio recorders to avoid mistakes. Translating the transcriptions from Portuguese to English was very time consuming. Thus only selected quotations were translated into English. The interview and field note transcripts were imported to Atlas ti5 (a computer assisted qualitative data analysis software package).

I printed all the transcripts and read them. Interesting points were highlighted by using a coloured pen. By identifying emerging categories and themes, I was able to produce memos, which were analysed in light of the literature review. I began to look for data patterns and a family of codes were built. Some of these codes collapsed into families of codes. Others were discharged. A list of final codes was then produced (Appendix 27). These codes were developed into theoretical concepts to be explored. For instance, data in the code 'dignity' led to an exploration of the meaning and definition of dignity from the point of view of patients, family members and palliative care professionals, as presented in Chapter Six. Data collection and analysis, construction of analytic codes and categories from data, and memo-writing were done at one and the same time. These

practices helped me to control the research process and to increase the analytic power of my work (Charmaz, 2006).

By adopting a grounded theory approach, I was able to compare and analyse the data and thus to construct analytic categories which informed my conceptual framework (Charmaz and Mitchell, 2001). Although I had subscribed to some aspects of grounded theory, I did not fully apply this approach to my data analysis. For instance, I did not employ saturation of data. The research sample was defined prior data collection, which contradicts grounded theory. The literature review was done before I had conducted my analysis as it enabled me to build my research questions, as well as to identify some potential relevant concepts like dignity. One of the major advantages of adopting a grounded theory approach was that it offered systematic strategies for analysing the data (Charmaz, 2006).

The next section will provide a detailed consideration about the plausibility and generalisability of the study.

3.8. The plausibility and generalisability of the study

Although concerns have been raised about the data rigor of qualitative research studies, as they tend to be small scale (Perakyla, 2008), it has been shown that they are able to ‘produce an intermediate type of limited generalization’ (Payne and Williams, 2005: 296) or what S. Williams (2000) refers to as ‘moderatum generalisations’. The notion of ‘moderatum generalisations’ as proposed by Williams (ibid) draws upon an

interpretivist tradition and thereby calls attention to the possibility of making theoretical inferences rather than empirical generalisations. 'Moderatum generalisations' as the term suggests are moderate. This means that 'the scope of what is claimed is moderate. Thus, they are not attempts to produce sweeping sociological statements that hold good over long periods of time, or across ranges of cultures'. They 'are moderately held, in the sense that a political or aesthetic view that is open to change.' (Payne and Williams, 2005: 297). By drawing conclusions from my data about the relationships that exist between categories of the phenomena being investigated I was able to make 'moderatum generalisations' (Williams, 2000: 218).

Thinking critically about the data was central to enhancing the generalisability as well as the plausibility of the study (Silverman, 2005). The latter refers to 'the degree to which the research process and theoretical formulations fit reality, provide understanding and are useful' (Hall and Callery, 2001: 260). The interview data collected was triangulated with the data collected from observations and this helped me to obtain an in-depth understanding of the phenomena being investigated (Walshe et al., 2004). Thick description demonstrated the richness of the data collected and showed that my accounts were reliable and internally valid. Also, this offers to the reader the necessary information to transpose the findings onto similar scenarios (Payne and Williams, 2005: 298). The incorporation of negative cases within the data increased my knowledge of the phenomena and enabled me to identify contradictions within the theory (Silverman, 2005).

The knowledge produced was independent of my background as recommended by Hewitt (2007). My female gender, white racial origin and middle class background did

not negatively affect my interaction with research participants. In fact, I think this might have helped my proximity with them as most of my research participants have a similar background. My 'pure' sociological identity (Li and Seale, 2008) has helped me to construct participants' accounts through a sociological lens. The dependability of the study was also guaranteed by the supervision process. The meetings held with the supervisor helped me to reflect and maintain objectivity.

3.9. Conclusion

The methodological aspects of the present study have been described in this chapter. A qualitative research process in the form of an ethnographic approach was adopted to address the research questions arising from the literature review. Participant observation was carried out over 10 months in two palliative care units for cancer and non-cancer patients and was complemented by interviewing techniques. In-depth interviews were conducted with 10 terminally ill patients. Twenty family members and 20 palliative care professionals were also interviewed. Verbal consent was obtained from the doctor and nurse chief for the observation of the communal areas and patients' private facilities. Also, verbal consent was obtained from staff for observation of team meetings and nursing handovers. Written consent for interviews was obtained on the understanding that participation was voluntary and that they could withdraw at any time without consequences. Participants were informed that their rights to anonymity, confidentiality and privacy would be respected. Interviews with terminally ill patients were conducted

at their bedside, while interviews with family members and palliative care professionals were conducted in a private area of the unit.

Listening with concern and compassion and maintaining eye contact were some of the strategies I employed to ease participants' concerns. Through touch I was able to ease the emotional distress of participants. The proximity to death was difficult for me to deal with and respond to as I had to integrate the feelings aroused in me by participants' experiences. Writing a journal, peer debriefing with colleagues, conversations with family members and friends and the practice of relaxation techniques helped me to deal with feelings of distress. The research process was very rewarding for me as it enabled participants to have their voices heard. The participation in research was found to be a cathartic and/or therapeutic experience for terminally ill patients, family members and staff. The computer assisted qualitative data analysis software helped me to organise interview and field notes transcripts. Grounded theory methodology helped me to control the research process and to increase the analytic power of my work (Charmaz, 2006).

I will now turn to the analysis and discussion of data. The next chapter, Chapter Four, is the first of a total of four empirical chapters, which present the findings of the current study.

Chapter Four

The experience of living with a visibly altered body: Men's and women's perceptions at end of life

4.1. Introduction

There has been a tendency within the literature to ignore how terminally ill patients deal with an altered physical appearance (e.g. Lawton, 2000). It cannot be straightforward assumed that physical appearance becomes less of a concern when one is dying. Important insights into this matter can be gained from the analysis of the existing literature on ageing bodies. There is evidence that appearance continues to be a matter of concern in later life (Hurd Clarke, 2002), even in the face of adversity caused by severe pain and incapacitation (Hurd Clarke et al., 2008). This is so because, regardless of one's age, appearance is understood as a form of social currency, in particular for women (Hurd Clarke, 2002). Women learn from an early age to view their bodies as objects of other's scrutiny, whereas men are taught to see their bodies as instruments of action (Franzoi, 1995). Within consumer culture - which sees the ideal female body as one that is youthful, thin and toned (Bordo, 1993; Brown and Jasper, 1992) - women are instructed to adopt instrumental strategies to combat deterioration and decay of the body (Featherstone, 1982).

The physical signs of ageing have been found to be more harshly judged in women than in men (Hurd Clarke, 2000). In addition to ageist beauty norms, this could be explained by sexist stereotypes (Hurd Clarke, 2000). There is a 'double standard about ageing' (Sontag, 1972) as society is more permissive with regard to the ageing of men and men's bodies than the ageing of women and women's bodies (Hurd Clarke and Griffin,

2008). This gender dimension might be particularly relevant in Portuguese society, as women's roles in Portugal have been found to be profoundly marked by traditional and reproductive domestic roles (Aboim, 2010; Andreotti et al., 2001; Karin et al., 2001; Lopes, 2006; Moreno, 2006; Tavora, 2012).

Research concerning the ways in which men and women who are dying experience their visibly altered bodies has been scarce. Not only has the importance of appearance at end of life been neglected, but also how gender defines and shapes the bodily experiences of terminally ill patients. This is surprising as women and men are socialized to perceive their bodies differently and to esteem different physical ideals and thereby their feelings and perceptions about their visibly altered bodies might be different. There is a need for a wider view of the interplay of gender and an altered physical appearance at end of life. I suggest that appearance is central for how men and women who are very ill and at the end of life construct and present their masculine and feminine identities and thereby I consider the doing of gender in the light of West and Zimmerman's (1987) work. The importance of physical appearance to both men and women's sense of self and identity should not be ignored in the literature on end of life and this chapter aims to present a discussion about this issue.

Hence, the present chapter asks the following questions: to what extent does a visibly altered body affect the self-identity of terminally ill patients? Does it differ by gender? Weight was one of the most salient body issues discussed within my interviews and thereby attention is paid in the first section of this chapter to how patients experience its loss. In relation to appearance, and following weight loss, the loss of hair was also one of the most common symptoms experienced by patients after cancer treatment and thus

a discussion of how it affects patients' self-identity is provided in the second section. A reflection on how an altered physical appearance can lead patients to be discredited by other people is presented in the third section. Issues of gender are placed under scrutiny whenever appropriate.

4.2. The meaning and significance of an altered bodily appearance: The case of weight loss

Weight has been found to be one of the most significant bodily concerns for men and women regardless of their age (Hurd Clarke et al., 2008). Given that women learn from an early age that looking good is a form of social currency (Brown and Jasper, 1993; Franzoi, 1995) it is understandable that weight and appearance are more significant concerns to women (Hurd Clarke, 2002). Women's concern with weight and appearance has been discussed in relation to the social obsession with thinness. Thinness is now a cultural exemplar of beauty, namely of female beauty (Hurd Clarke, 2000). As Bordo (1993: 37) pointed out: 'as slenderness has consistently been visually glamorized and as the ideal grows thinner and thinner bodies that a decade ago were considered slim have now come to seem fleshy.' Weight gain and fatness is in this light seen as a moral failure and laxity, and body weight as a matter of personal choice and responsibility (Hurd Clarke, 2000).

The idea that thinness is attractive, desirable and healthy (Brown and Jasper, 1993) has remained unchallenged within sociological literature. This association nevertheless

might not make sense in the face of a life-threatening or terminal illness. Instead it might signal a loss of control over the body. Weight loss induced by cachexia - muscle wastage and altered metabolism - has been described as one of the most common and irreversible symptoms experienced by patients with a terminal illness (Poole and Frogatt, 2001; Shragge et al., 2006; Shragge et al., 2007; Strasser et al., 2007; Wilcock, 2006). Little is known however about how unintentional weight loss is experienced by those who are very ill and at the end of life (Hopkinson et al., 2006). The aim of this section is to make a further contribution to the literature by providing an understanding of terminally ill patients' perceptions and feelings about their weight loss and thus about their visibly altered body.

Half of the patients (five out of 10) in this sample had suffered from a considerable loss of weight. These patients expressed their discontent with their visible weight loss in the interviews I conducted with them. For instance, a 72-year-old woman with ovarian cancer stated that she felt bad about her physical appearance due to her loss of weight and thereby she could not look at herself in the mirror:

Bella: After a while I lost a lot of weight.

I: How do you feel about it?

Bella: Horrible! Everything is falling down!

I: Are you saying that you do not like to see your reflection?

Bella: Thank God I cannot see myself in the mirror! There are no mirrors here [i.e. at the palliative care unit]!

(Bella, terminally ill patient)

Like for the women in Hurd Clarke's (2001) study, for this woman mirrors and her reflected image were a source of anxiety as they reinforced the visibility of her altered physical appearance. The women in Hurd Clarke's (ibid) study described the conflicted relation between their sense of self and their ageing body, and in doing so, established a distinction between their perceived identity and their physical self or appearance. The outside self was spoken about in Hurd Clarke's (ibid) study as a physical container of the inside self which is hidden within the ageing body or what Featherstone and Hepworth (1991) would refer to as the mask of ageing which concealed the youthful self beneath. In contrast to the women in Hurd Clarke's (2001) study, the woman above did not directly speak about a separation between her inside and outside self. This contradicts Hurd Clarke's (ibid) thesis that the dissatisfaction with visible weight loss is very much related with the fact that appearance no longer reflects one's true self. The sense of dissatisfaction with weight loss was magnified in an account provided by a 52-year-old man with esophageal cancer, which showed how visible weight loss can be a source of personal embarrassment:

I became very skinny. The clothes did not fit me. Then [at home] I saw myself in the mirror: 'Oh! What's this! Fuck! They [i.e. the radiotherapists] will now burn me! [i.e. Ben was so slim that he thought that the radiotherapists would burn what was left of his body] Then people said: 'You look crystal clear! Any day you will pass through the middle of the rain!' These kinds of jokes from friends. We laugh but inside I thought they were right.

(Ben, terminally ill patient)

The comments made by Ben's friends about his altered physical appearance constantly reminded him about his poor health. This is reminiscent of Reid et al.'s (2009: 611) study on the lived experience of cachexia, where it was found that for patients' their wasted appearance caused feelings of self-consciousness and made it harder for them to engage in social interaction without being reminded by others that they were ill. Further, a 69-year-old woman with esophageal cancer who had lost 32 kilograms stressed the impact that her visible weight loss had on her caring relatives as they could not stand looking at her:

My husband and my daughter-in-law have no courage. They haven't the courage to look at me. My daughter-in-law only changed my diaper once. She said to my husband: 'I have no courage to see it.' When he took off my clothes to change me he did not look at my belly. He did not want to see my belly because of the way I was.

(Bridget, terminally ill patient)

In the account above Bridget clearly showed that she was aware of the impact that her visible weight loss had on her loved ones. The visibility of weight loss was a barrier to her social engagement with significant and non-significant others. I was also quite surprised when I saw Bridget as she looked like a living corpse. A similar view was expressed by some members of staff when they spoke about Bridget as they were quite shocked with her visible weight loss. The spectacular appearance of thin bodies is in this light viewed with horror and associated with extreme suffering (Gooldin, 2003; Warin, 2004). The slenderness of terminally ill patients' bodies appeared to contradict the prominent idea within western culture that thinness is attractive or desirable (Brown

and Jasper, 1993: 16; Bordo, 1993). Western culture's hierarchy of beauty which privileges the thin (Kwan, 2009) is thrown into doubt by the bodies of terminally ill patients.

Weight in consumer culture has been regarded as an indicator of health in the sense that health becomes visually accessible via the parameters of the body (Growing et al., 2013: 267). Within this cultural context the slim body is seen as a marker of self-control, whereas the overweight body signifies self-indulgence and a lack of self-discipline (ibid: 267). In the face of the unintentional weight loss experienced by terminally ill patients, not only is the link between slenderness and control challenged, but also the aesthetic of health which is based on the assumption that a thin body is a reflection of well-being (Jutel, 2005; Growing et al., 2013). Thinness is no longer taken to represent a sign of 'good health' (Kwan, 2009; Rich, 2011). The experience of patients with a terminal illness draws some parallels with the experiences of women who suffered from anorexia nervosa, as interviewed by Rich (2006): their health and well-being is reduced to a matter of weight gain.

The wasting away of the body was very difficult to watch, in particular for family members (Seale, 1998). The wife of a 58-year-old man with lung cancer who stated that her husband's loss of weight had transformed his physical appearance in such a way that he looked older acknowledged how painful it was for her to watch her husband's unintentional weight loss:

Abby: My husband is 50-years-old and he looks like a person of 80.

I: Why do you say that?

Abby: Well, now his face is rounder because he is taking cortisone but his body is a skeleton. It is very hard to see. Especially for those who once knew him. Now he looks like a skeleton.

(Abby, wife)

This wife by stating that her husband looked like a skeleton illustrated the extent to which the thin body was an extreme body: one that defies the limits of human capacity (Warin, 2004). The idea of a 'living skeleton' is reminiscent of Gooldin's (2003) notion of the 'living death'. This represents an 'in-between corporeality' in which the 'living (social) persona' is enclosed in a 'death (physical) body' (ibid: 42). Thinness was a precursor of the inevitability of death (Hopkinson et al., 2006; Reid et al., 2009) not only for family members, but for patients themselves (four out of five who suffered from cachexia outlined it). This point is well illustrated in Bridget's following comment that her visible weight loss had prompted concern about her advanced illness and impending potential death:

Bridget: In the first few days [when she was at the hospital] I did not look in the mirror. I went alone to the shower only after a month or two. Then I began to stare at my feet. I looked at myself. Well. After a while we look at ourselves.

I: What did you think when you had a look?

Bridget: I thought I would die like others.

I: Did you think at the time that you were pretty bad?

Bridget: I was. If they did not take care of me in the hospital at that time I would pass away.

I: It was difficult for you to see yourself as being so slim?

Bridget: It was very difficult indeed. Just I and God know how much.

I: What did you think?

Bridget: I thought I would die. I thought I will never see my grandsons. Just mothers and grandmothers worry about such things.

(Bridget, terminally ill patient)

As outlined previously, visible weight loss was perceived as a symbol of advanced illness and proximity to death. This outlines Bury's (1988) conceptualization of meaning as significance as it refers to the significance and connotations associated with unintentional weight loss. There was nevertheless an exception. This draws a parallel with existing research (McClement et al., 2003; Poole and Froggat, 2002; Strasser et al., 2007), which suggests that more often than not patients and their families do not understand the decrease in food intake and unintentional weight loss as an inherent part of the dying process. The following account confirms that this 78-year-old man with lung cancer did not relate his weight loss to illness progression and potential impending death:

Billy: I am much thinner. I have lost a lot of weight because of my lack of appetite. I can't eat. I just eat a little bit.

I: But do you have pain when you eat?

Billy: No. I just don't have an appetite. I can only eat half of the plate. When I am alone I eat less. When they [professionals] are here with me they talk and it is easier. I am not saying that they insist I eat. Here they don't do that. They say: You only eat what you want.

(Billy, terminally ill patient)

The findings presented here contribute to a better understanding of how a wasted appearance can be very troubling to terminally ill patients as well as for those who accompany them. This is important as it has been suggested elsewhere (Lawton, 2000: 103) that physical appearance is no longer a matter of concern for patients with a terminal illness. Unlike previous reported research (Hurd Clarke, 2000; Hurd Clarke,

2002; Hurd Clarke et al., 2008), I did not find sufficient evidence that confirms that weight is a more important issue for women than for men. As women learn from an early age to perceive their bodies as an object that others aesthetically evaluate (Franzoi, 1995: 417; Bordo, 1993) it could be expected that an altered physical appearance would be more of a matter of concern to female patients than to their male counterparts. As weight loss is one among many other symptoms experienced by terminally ill patients whose physical appearance alters, there is a need to explore how other symptoms and their treatments which visibly alter the patient's body impact upon their sense of self and identity. Attention needs to be given to how masculine and feminine norms might shape and constrain this experience. It is to a more detailed consideration of this that I will now turn.

4.3. A look at how bodily appearance matters at end of life

Appearance has been found to be integral to our sense of self and identity (Ward et al., 2014) and its management to be an important aspect of doing gender across the lifecourse (Hurd Clarke and Griffin, 2008). Research on how patients with a terminal illness deal with a visibly altered body and how this is constrained by gender norms has been scarce. The aim of this section is to provide new insights about this matter. Alongside weight loss, hair loss has been described as one of the most common visible bodily changes experienced by terminally ill patients, in particular by those who had undergone cancer treatments like chemotherapy (Batchelor, 2001; Rosman, 2004).

What became evident in my own findings was that men and women were likely to experience hair loss following chemotherapy in dissimilar ways. Although there were a few exceptions, the men in this sample dealt with hair loss more easily than the women. This could be related to the fact that baldness is more socially acceptable for men (Batchelor, 2001). A 58-year-old man with prostate cancer spoke about his hair loss as follows:

Hair loss was not a big problem to me. Because I look at other people and say: well, another bald head.

(Brad, terminally ill patient)

Like the men in Rossman's (2004) study, this man 'played down' and 'banalised' his hair loss. Thus he diminished the impact that baldness could have had on his everyday life (ibid: 338). A similar strategy was used by a few women in this sample, who saw hair loss not only as an 'inevitable consequence of treatment' but as a 'price to pay for being cured' (ibid: 336). A 69-year-old woman with esophageal cancer showed a lack of concern with her hair loss:

The thing that cost me less [in terms of her changed physical appearance] was the loss of my hair. The loss of my hair was the thing that cost me less because people told me that this would happen. I've seen them bald [the other patients at chemotherapy] so I knew the result. I was not concerned with hair. If God wants it will grow. Then it will grow more beautiful than ever...more strong... more beautiful.

(Bridget, terminally ill patient)

Also, a 65-year-old woman with Merkel Cell carcinoma indicated a lack of concern with hair loss, namely in showing her discredited attribute (Goffman, 1963) to other people who became aware of her illness, as she was more worried about the treatment outcome:

Brenda: I didn't give much importance to the loss of hair. There are people who say that this is what has been dramatic for them. But I didn't give it so much importance. When people asked me...Because they saw me...I told them: I wish that my hair was the worst thing. Because hair grows. Many people are concerned with hair loss, I'm not. I was more concerned with another aspect.

I: Which aspect?

Brenda: In terms of becoming unwell. Because the hair grows and there is no problem with that.

(Brenda, terminally ill patient)

In contrast, for another two women hair loss was found to be a very dramatic experience. A 72-year-old woman with ovarian cancer pointed out that due to hair loss she was no longer able to look at herself in the mirror. As a way to cope with her hair loss and to become discreditable (Goffman, 1963) this woman decided to wear a wig and some scarves:

Bella: I lost my hair twice and it has grown back again. This happened because I had several rounds of chemotherapy. The hair fell out and grew back. Now it has fallen out but is taking a much longer time to grow.

I: How did you react when you lost your hair?

Bella: With sadness. I immediately bought a wig. I could not look in the mirror and see myself without hair. I bought a wig and some scarves to put on my head.

I: Do you feel better with or without the scarf?

Bella: I feel better without the scarf. But if I go outside I put the scarf on my head.

(Bella, terminally ill patient)

The wearing of a wig as a way to gain a sense of comfort was also acknowledged by a 78-year-old woman with ovarian cancer, who stated that her loss of hair has been harder for her as she always liked to look nice and hair was an important aspect of her self-presentation:

Becky: This is not the first time I've lost my hair. I lost my hair several times when I had chemotherapy. So I am used to it now.

I: How did you react to it at first?

Becky: It was hard.

I: Why?

Becky: Because I like to look nice. I bought a wig. The wig gives me a certain comfort. I put the wig on when I go out [of the unit].

(Becky, terminally ill patient)

As in Rossman's (2004) study, a wig, a scarf or a hat was worn by a few women in the current study in the presence of people outside their closest network of family and friends with whom they do not want to share their illness and show their vulnerability. The stigma of hair loss is not immediately visible and thereby they are in Goffman's (1963) terms 'discreditable'. The strategy of partial camouflage (Rossman, 2004) - where the patient decides when to hide his/her hair loss - was spoken about by the

husband of a 62-year-old woman with a malignant glioma (i.e. a tumour of the central nervous system) who indicated that a major concern for his wife was not showing her loss of hair to other people:

My wife was always very careful about not showing others that she had lost her hair. She always wore a wig or something else to hide her hair.

(...)

The loss of hair was not a very big thing. But symbolically it was huge to her. Before her hair fell out, during the two or three days, between the diagnosis and the surgery she went with a friend, and with me although I stayed in the car, to buy a wig. It was important for her to maintain her hair. To maintain her appearance.

(Andy, husband)

Hair loss was understood by Andy's wife as a symbol of her life-threatening illness - something that she wanted to conceal. Through the use of a partial camouflage strategy, namely the wearing of a wig, Andy's wife wished to pass for normal (Charmaz, 1991) and thus to manipulate others' impressions of her (Rossmann, 2004). The desire to appear to others as unchanged is similar to that experienced by women who have had a mastectomy due to breast cancer and used a handkerchief in a breast pocket or had gone through reconstructive surgery as a means to regain the familiar appearance of their body image (Crouch and McZenzie, 2000). The comment made by the sister-in-law of a 78-year-old woman with ovarian cancer also draws attention to the fact that the wearing of a wig depends of the presence of what Goffman (1963) referred to as the 'initiates' and the 'non-initiates'. In the presence of 'non-initiates' - i.e. those with whom she do not want to share her visible stigma (Rosman, 2004) - such as people outside the

palliative care unit this woman decided to wear a wig or a hat, as the account of her sister-in-law indicated:

She continues to wear the wig when she goes to the hospital. Now she goes in the ambulance. The other day she told me that she felt better with the hat because her wig moves on her head. The hat is more comfortable for her.

(Angela, sister-in-law)

The women in this sample who choose to hide their hair loss from other people's eyes were able to protect themselves from anticipated negative reactions (Bachelor, 2001; Rossman, 2004; Munstedt et al., 1997). The attempts made by these women to show positive images of themselves - what Goffman (1963) called 'impression management activities' - enabled them to present to others desired forms of identity (Balfe and Brugha, 2010). Like existing research on the experience of chronically ill women (Bredin, 1999; Crouch and McZenzie, 2000), I found that the maintenance of a normal physical appearance was understood by the women in this sample as an indication that the disease was controlled and passing (Charmaz, 1991: 68).

The need on the part of female patients to present a socially acceptable image (Ballard et al., 2009) was also evident in their engagement in what Gilleard and Higgs (2000) called 'passive acts of consumption' such as hair dyeing. For instance, a 68-year-old woman with an occult tumor, who was bed-bound due to bone metastases, pointed out that she was very happy with the fact that she had recently dyed her hair and thus was able to mask her grey hairs:

I: Did you lose your hair?
Beatrice: No. But I dyed my hair here [at the palliative care unit].
I: Do you like to have nice looking hair?
Beatrice: Yes. I also would like to cut my hair. I don't want it to lose its strength.
I: Your hair is very nice.
Beatrice: It is brown, a very light one.
I: Don't you like it?
Beatrice: Yes! Yes, I like it!
I: But did you change your color?
Beatrice: It was a darker brown.
I: Why did you decide to dye it?
Beatrice: Because I had some grey hairs.
(Beatrice, terminally ill patient)

Through the use of hair dyeing this woman was able to maintain an image that supported a form of continuity against the backdrop of physical change (Ward and Holland, 2011). While grey hair is one of the most readily apparent markers of chronological age (Hurd Clarke and Korotchenko, 2010), it is also one of the easiest aspects of appearance to disguise through beauty work interventions such as hair dye (Hurd Clarke and Griffin, 2008). Existing research on ageing has suggested that grey hair is associated with physical decline and impending mortality (Ward and Holland, 2011; Hurd Clarke and Korotchenko, 2010). Indeed it has been found that grey hair more often than not leads to feelings of social invisibility in the sense that women tend to be discounted or marginalized for appearing old (ibid). Like for the women in Hurd Clarke and Griffin's (2008) and Hurd Clarke and Korotchenko's (2010) studies, for this woman the use of hair dye was a source of personal satisfaction, as her husband's comment shows:

My wife wanted to dye her hair. I asked the team: ‘How you will do it?’ They told me: ‘Don’t worry. Just bring the color and we will do it’. And they did it! They dyed her hair! She was very proud! She was never a vain person. But she was very happy with it (i.e. the hair dye)!
(Albert, husband)

Hair care practices have been found to play an important role in women’s lives regardless of their age (Hurd Clarke and Griffin, 2008; Hurd Clarke and Korotchenko, 2010; Ward and Holland, 2011). Hurd Clarke and Korotchenko (2010: 1024) noted that going to the hair salon or dyeing one’s hair enabled women to feel better about themselves and their personal life circumstances. Within this study the importance that women tended to place on hair and hair-care practices appeared to be very much related with processes of socialization and enculturation as it reflected ingrained habits (Kontos, 2006). A few (three) family members indicated the wish of their family members to go to the hair salon to style their hair and thereby demonstrated how appearance, and specifically hair and hair-care practices, can be an arena for resistance and continuity in the face of adversity (Ward et al., 2014). The husband of a 70-year-old woman with a multiple myeloma spoke about his wife’s need to style her hair in the following way:

The other day she told me: ‘I need to style my hair!’ I told her: ‘Whenever you want’. She wants to look good. This means that she is still concerned with her appearance. I think this is great!
(Alvin, husband)

Even the women in this study who were not worried about their loss of hair - namely Brenda and Bridget - showed concern with the maintenance of a good looking appearance. For instance, Brenda - whose hair had recently grown - spoke about her wish to go to the hair salon to style her hair as well as the need to remove some of her facial hair:

Brenda: I would like to go to the hairdresser.

I: I think they have it here. Do you know?

Brenda: Yes. I would ask her to come here to cut my hair. I also have some hair on my face. With age it worsens. I would like to do my moustache. Now we say fuzz. I have a lot of hair there.

(Brenda, terminally ill patient)

Hairlessness has been found to be not merely a trivial women's beauty routine, but a significant feature of the construction of femininity (Toerien and Wilkinson, 2003: 341) and thereby it is not surprising that this woman emphasised the removal of her facial hair. Hairlessness indeed serves to construct the 'appropriately' feminine woman (ibid: 333). What has to be taken into account here is that body hair removal was an important form of personal care for this woman and that it could enhance her sense of femininity. The accounts provided by a few (four) family members indicated that women's maintenance of a good physical appearance supported a form of biographical continuity (Ward et al., 2008). The sister-in-law of a 78-year-old woman with ovarian cancer put it in the following way:

She always liked to look good. Even today she likes to look good. Today I brought her cream and she put it on her hands. She always liked to look good. She never liked to look bad to others.

(Angela, sister-in-law)

Similar to Hurd Clarke et al. (2008), I found that physical appearance is still a matter of concern to most women in this study despite their increased pain and incapacitation. This finding is not in accord with that of a previous study conducted by Hurd Clarke (2002), where it was noted that the attention that women tend to give to their physical appearance declines when they face serious health issues. Women's focus on appearance has been discussed in relation to consumer culture (Featherstone, 1991) as they are more likely to feel the pressure to hide the visible signs of ageing (Hurd Clarke, 2001). There is a 'double standard about aging', where older bodies are found to be more disadvantageous to women (Sontag, 1972). The relationship between physical appearance and women's identity was directly spoken about by four members of staff.

Their comments were akin to that of a spiritual and religious assistant:

Having nice hair is very important for these women. Painting their nails and using their perfume is also very important. They know that they will not be as they were before. But this improves their appearance and their appearance is very important to their identity. This is more important when their relatives come to visit them. In a way this concern with appearance helps them to feel alive.

(Capri, spiritual and religious counselor)

What also needs to be taken into account is that through hair care and other beauty work practices the women in this sample were able to 'do gender' (West and Zimmerman,

1987). Drawing upon West and Zimmerman's (ibid: 126) argument that 'doing gender involves a complex of socially guided perceptual, interactional and micropolitical activities that cast particular pursuits as expressions of masculine and feminine natures', I suggest that the behavior of the men and women in this sample towards their physical appearance was guided by masculine and feminine norms. Women are more likely to be judged by other people on the basis of their aesthetic value (Bordo, 1993; Brown and Jasper, 1993) and therefore the greater importance female patients in this sample tended to place on the maintenance of a good physical appearance was not surprising. In contrast, the men did not appear to be particularly concerned with the maintenance of a good physical appearance. This is understandable as men tend to follow an instrumental orientation towards their bodies and thus to perceive function (as will be outlined in the next section, namely in the discussion about the importance that male patients gave to their work experience) as more important than physical attractiveness (Hurd Clarke et al., 2008).

As women learn from an early age to view their bodies 'as an object of discrete parts that others aesthetically evaluate' (Franzoi, 1995: 417) it was also not surprising that the women in this study showed a great concern with clothing (Hurd Clarke et al., 2009). The comment of the husband of a 62-year-old woman with a multiple myeloma illustrates this:

She likes to be well-groomed. She always had some concern. She asked for her clothes... her lipstick... her rouge. Here they also don't like people to be in their pyjamas all day. But she does not even wear a tracksuite. She wears her own trousers, her own blouses. She chooses her own clothes. She matches the colours. She has some concern.

(Andie, husband)

Clothing has been found to be central to the performance of a socially and personally acceptable femininity - it allows women to construct and project desired images of the self (Hurd Clarke et al., 2009). Regardless of one's gender, clothing enables men and women to express their identity to the outside world and, at one and the same time, to reinforce it at a physical level (Twigg, 2009). Clothing, as Twigg (2007: 286) argued, 'mediates the relationship between the body and the social world, forming the vestimentary envelope that contains and makes manifest the body, offering a means whereby it is experienced, presented and given meaning in particular contexts'. Clothing in this light could be seen as a form of 'masquerade' (Ballard et al., 2005; Biggs, 2004) that is central to how men and women perform a socially acceptable femininity and masculinity (Hurd Clarke et al., 2009). Also, clothing offers to male and female patients a way of 'concealing or diminishing the perceptibility of the supposed abominations of the body' (ibid: 711) inherent to the process of bodily deterioration and decay. That is, clothing enables them to mask their bodily transgressions (ibid) and thus to pass for normal (Goffman, 1963).

The practices of dress have been found to be shaped by cultural and social norms regarding the presentation of self in everyday life and our intimate experience of our bodies and thus dress is seen as a situated bodily practice (Entwistle, 2000: 11). As one of the principal means we present and see the body is through clothes (Twigg and Buse, 2013) it is understandable that clothes act to define and naturalise gender (Twigg,

2007). What men and women wear draws upon socially constructed norms of gender (Lunceford, 2010) and thereby dress provides a clear example of what Butler (1993) called the 'performance of gender'. As all the patients in this study wore their own clothes - and taking into account the fact that women gave more importance to clothing than men - both male and female patients were doing gender (West and Zimmerman, 1987) by presenting their bodies according to cultural and social expectations (Twigg, 2007). The fact that patients wore their own clothes was very much related with the policy of the palliative care units where this study was conducted as they believed that the wearing of patients' own clothing would simulate a more home like environment. Enabling patients to wear their own clothes may provide a sense of biographical continuity for their family (Ward et al., 2008) as well as supporting a form of embodied identity and personhood at end of life as it signifies to the social world who and what the person is (Twigg and Buse, 2013: 327, 330 & 331).

What has to be taken into account here is that terminally ill patients were able to exercise agency (Hurd Clarke et al., 2009) and to maintain their gendered identities (West and Zimmerman, 1987). This contradicts Lawton's (2000: 166-167) theory that these patients are not able to perform their gender and experienced a disinvestment of their sense of masculinity and femininity alongside the process of bodily deterioration and decay. Appearance, as outlined previously, is an important aspect of doing gender at end of life (West and Zimmerman, 1987), but it could also be a powerful vehicle for discrimination against those who are dying.

A more detailed consideration about this latter point will be presented in the next section.

4.4. The stigma of having a visibly altered body

A visibly altered body brings with it the experience of stigma in the sense that terminally ill patients might feel negatively evaluated by other people on the basis of their physical appearance. The possession of a visibly altered body distinguishes patients from others who are visually considered to be 'normal'. Stigma signals an 'ontological deficit' (i.e. a sense of being imperfect) and it refers to a social process which is characterized by exclusion, rejection, blame or devaluation, that results from an adverse social judgment based on an enduring feature of identity (Scambler, 2009: 441). This negative evaluation may be felt or enacted. While the latter refers to feelings of discrimination on the grounds of not being 'normal', the former refers to the internalized sense of shame and anticipation of 'enacted' stigma (Scambler and Hopkins, 1986). Despite the recognition within sociological literature of the stigma attached to living with chronic or life-limiting illness (Scambler, 2009), few authors apart from Lawton (2000) have paid attention to this concept in relation to end of life. There has been a paucity of research on how terminally ill patients may be discriminated against by other people on the grounds of their visibly altered body. The purpose of this section is to remedy this gap.

The idea that a visibly altered body is deeply discrediting was present in some of my interviews and field note transcripts. For instance, a doctor directly stated that an altered physical appearance results in the stigmatization of terminally ill patients by other people:

Carmen: I think our physical appearance defines our relations with society. When we have a visible alteration society ends up asking why it is so. I think this is why people become more isolated. That is, because they do not want to give an explanation.

I: Do you mean that there is a stigmatization?

Carmen: Yes, indeed! I think this is so in most cases. Well, although it isn't necessary verbal. The non-verbal in certain circumstances is very intense.

I: In what sense? Do you refer to the way others look at the person?

Carmen: Yes! Exactly! I think the way others look ends up leading to these feelings [of being discredited]!

(Carmen, doctor)

The above account suggests that the behaviors of other people contribute to patients' feelings of being discredited on the grounds of their altered physical appearance or what Goffman (1963) would refer to as the 'abominations of the body'. This sense of enacted stigma has also been described by Lawton (2000: 44), who noted that when patients became visibly unwell they ceased to be treated by others as 'normal'. In a similar way to Lawton (ibid: 148), I found that withdrawal from contact with terminally ill patients stemmed from the stigmatizing effects of illness, as well as from the knowledge of patients' impending potential death. This became particularly evident in my field note accounts. During a nursing handover a nurse commented that she was worried by the fact that the friend of a 46-year-old man with brain cancer - who was visibly unwell due to several edemas that produced swelling - had decided to stop visiting the patient with the excuse that he no longer could be confronted with his friend's vulnerability. This inevitably reminded him of his own vulnerability and his own illness - as he was suffering from a life-threatening illness:

Today in the nursing handover, Cecilia (nurse) mentioned to other staff members that Abel, a friend of Barney, who suffered from a lymphoma, had told her that he was not able to see Barney anymore because it was a constant reminder that this could happen to him. Cecilia was concerned that Barney's friends had stopped visiting him because of his terminal condition and that this might increase Barney's sense of isolation.

(Extract from field notes)

In the face of dying and its bodily realities, extended family members and friends feel that their sense of safety or what Giddens (1991) referred to as 'ontological security' is threatened. The person's confidence in their life trajectory is lost. Thus they are forced to reflect on their biographies and the circumstances of their own death (Broom and Kirby, 2013: 510). Disconnection from dying and its bodily realities appear in this light to be a better option than confrontation with it. As Fife and Wright (2000: 52) argued, 'the stigma associated with cancer is thought to be driven primarily by the fear of the illness itself, or a perception that it could happen to me.' Cancer - the most common illness amongst the patients in the current study - has been associated with certain negative myths and images and therefore carries with it a strong symbolical meaning (Sontag, 1978).

Previous research has suggested that advanced cancer patients are likely to experience feelings of being contaminated or branded (Chapple et al., 2004; Mathieson and Stam, 1995). While the patients in this sample did not report such feelings, the aversion by their peers towards them on the grounds of their altered physical appearance was evident. The story told by a nurse during a team meeting about a 68-year-old woman

with an occult tumor, who refused to have any close contact with a 66-year-old woman with cancer of the tongue, who had a malignant wound on her face, illustrates this point well:

In the team meeting held today Ciara [nurse] told the team that Beatrice has stigmatized Barbara. This happened when Barbara went to Beatrice's room to say hello. Ciara explained that when Barbara was near the bedroom door Beatrice stopped Barbara by saying that she did not want to know anybody who was sicker than her. Barbara was very upset and went back to her room without talking. Later in the afternoon in a conversation with her sisters Beatrice had said that Barbara was sicker than her because her cancer had become visible. The team was very concerned about Barbara. They feared that this episode may have increased Barbara's feelings of being isolated because of the visibility of her illness.

(Extract from field notes)

The above extract is also very interesting in that it suggests that the aversion of others towards patients' visibly altered bodies may lead to feelings of social isolation and exclusion (Fife and Wright, 2000). This is in accord with the theory proposed by Goffman (1963), who said that those who have more salient bodily differences become more severely stigmatized. The patients in this study were nevertheless able to escape from potential stigmatizing situations by limiting their social contact with others who they knew would discredit them on the grounds of their altered physical appearance (MacRae, 1999). The account given by a 59-year-old man with cancer of the liver, who at the time of the interview was wheelchair bound due to bone metastases, illustrates this issue:

At first, being sick affected me a little. People that I had problems with and who I didn't talk to, came to my home to see me. This affected me. I even told my uncle that these people wanted to go to my home to enjoy seeing me in this situation. So due to this I didn't want visits from anyone.

(Bob, terminally ill patient)

Existing research on chronic illness similarly indicates that the stigma felt by chronically ill people derives from the behavior of others towards their physical difference (Camp et al., 2002; Taleporos and McCabe, 2002) and thereby they were likely to limit their social contacts to those they believed would not devalue, reject or exclude them (Chau et al., 2008; Nijhof, 1995). This sense of shame and fear of being discriminated against on the grounds of a visibly altered body have also been found to be at the center of the discourse of a few (four) members of staff when they spoke about the main reasons for patients limiting their social connections to their immediate family. A nurse explained why patients' relationships with extended family and friends often cease at the time of dying due to this felt stigma (Scambler and Hopkins, 1986) as follows:

When they have a 'traditional family structure' normally relationships became stronger. The family tried to help and to be more present. I am talking about the immediate family. In terms of the social network like friends I think there is a withdrawal. I think this is mainly promoted by patients and their family members. This is because patients don't want others to see them in such a poor condition.

(Ciara, nurse)

This sense of felt stigma also became apparent in the accounts of family members, like that of the wife of an 82-year-old man - who had been in a vegetative state after a stroke episode - when she explained why her son had decided to limit his father's social contacts:

My son did not want his father's colleagues to visit him so they could not see his degradation. So they remember his father the way he was. Only close friends and our family have come to visit him.

(Adrianna, wife)

One might speculate about whether Adrianna's son was experiencing a stigma of affiliation (Gray, 1993) - or what Goffman (1963) called courtesy stigma - because of his biographical relationship with his father and his known-about identity (Gray, 2002) as the son of a man with a visibly altered body who is dying. This discreditable stigma (Goffman, 1963) could be augmented because Adrianna's son like his father was a judge and therefore many of his father's colleagues were or had been his colleagues as well. Through information control Adrianna's son was able to avoid courtesy stigma (MacRae, 1999). There is ample research evidence showing that when one member of a family has a stigmatizing illness, other members experience courtesy stigma and thereby are likely to employ strategies to cope with it (ibid: 55; Gray, 1993; Scambler and Hopkins, 1988).

The degree of social distance (i.e. of familiarity) between the discredited person and the audience making the judgment about his/her behavior has been found to influence stigma (Jones et al., 1984). This might well explain why people at the closest relational

distance with the patient such as their immediate family members were less likely to stigmatize him/her (MacRae, 1999). In Goffman's (1963) terms, immediate family members for most patients served as a protective circle as long as they were in their presence they did not need to be concerned about the judgments of others on the grounds of their visibly altered body (MacRae, 1999). My findings challenge the arguments of Lawton (2000), who said that family members tend to discredit patients when they became 'visibly unwell' and were only supportive and attentive on occasions when they 'looked and acted normal' (ibid: 44-45). This was the case, for instance, with Barbara - a 66-year-old woman with tongue cancer who had a malignant wound on her face - whose daughter cared for her while she was at her home, as her account convincingly shows:

Barbara: I changed my mother's bandage every day. She had them [wounds] in two places - one here and another there. There was pus everywhere. I changed it every hour.

I: How you deal with it?

Barbara: I did it with love...with care. What upset me more was to see my mother suffering. It did not bother me helping her, but to see her suffering.

(Barbara, daughter)

This was an example amongst many others in my interview and field note transcripts that showed the way in which immediate family members were very supportive of patients who had a visibly altered body. This led me to conclude that terminally ill patients were not discriminated against and, ultimately, abandoned by their immediate family - in contrast to what happened in relation to their extended family and friends -

on the grounds of their altered physical appearance and their status of being terminally ill.

4.5. Conclusion

The findings presented here contribute to a better understanding of how terminally ill patients and those who accompanied them in their last moments experience and deal with a visibly altered body. To date, research that has addressed such concerns has been scarce and has not properly taken gender into account. This is quite surprising as the literature on ageing and chronic illness has convincingly showed that an altered physical appearance may have a profound impact on one's sense of self and identity and that this impact may vary according to one's gender. The research questions asked at the beginning - To what extent does a visibly altered body affect the self-identity of terminally ill patients? Does it differ by gender? - have been addressed within the three sections of this chapter.

Firstly I paid attention to the meaning and significance of a visibly altered body for patients as well as for their loved ones. Visible weight loss was a profound source of dissatisfaction for the patients in this sample. It was a barrier to patients' social engagement with significant others as it constantly reminded them that they were ill (Reid et al., 2009). Patients' bodies were viewed with horror and associated with extreme suffering (Goldin, 2003; Warin, 2004) and contradicted the prominent idea in modern western society that thinness is attractive or desirable (Brown and Jasper, 1993; Bordo, 1993). Thinness in this context was seen as a precursor to deterioration and a

reminder of the inevitability of death (Hopkinson et al., 2006; Reid et al., 2009). I found that weight loss was very troublesome for patients, as well as for their family members (McClement et al., 2003; Poole and Froggat, 2002; Strasser et al., 2007). Indeed it was particularly painful for certain family members to watch the wasting away of the body (Seale, 1998).

Unlike what has been described within the literature (Hurd Clarke, 2000; Hurd Clarke, 2002; Hurd Clarke et al., 2008), I did not find significant gender differences in relation to the meaning and significance attributed to weight loss and therefore my findings contradict theories (ibid) that have suggested that weight is a more important issue for women than for men. A different picture emerged however when discussing hair loss as I found that this was a more painful experience for the women than for the men in this study. Women were likely to use certain camouflage strategies such as a wig, a scarf or a hat (Rosman, 2004) in the presence of what they considered as ‘non-initiates’ (Goffman, 1963) as a means to pass for normal (Charmaz, 1991). I noted that hair care practices were very important for the women in this sample as it supported a form of biographical continuity (Ward et al., 2008). These ingrained habits (Kontos, 2006) could be explained by processes of socialization (Hurd Clarke and Korotchenko, 2010; Ward and Holland, 2011) as women learn from an early age to be concerned with their appearance as they would be evaluated by others on such grounds (Brown and Jasper, 1993; Franzoi, 1995). The findings of the current study contrast with previous research that has claimed that the attention that women tend to give to their appearance declines with the onset of serious health issues (Hurd Clarke, 2002). Appearance was found to be an important instrument for doing gender at end of life (West and Zimmerman, 1987),

namely through the presentation of self in everyday interaction according to feminine and masculine norms (Entwistle, 2000; Twigg, 2007; Twigg and Buse, 2013).

A visibly altered appearance was also found to be an important mechanism of discrimination. Echoing Lawton's (2000) findings, I observed that a few patients in this study were discriminated against by others on the grounds of their altered physical appearance. In accordance with existing research on chronic illness (Camp et al., 2002; Chau et al., 2008; Nijhof, 1995; Taleporos and McCabe), I found that the stigma felt by terminally ill patients derived from the behavior of others towards their physical difference and thereby they tended to limit their social contacts to those who they believed would not disqualify them, namely to their immediate family. Unlike Lawton (2000), I did not find that terminally ill patients were discredited by their immediate family when they became visibly unwell. This contrasts with the reaction of extended family members and friends, as I noted that they were likely to avoid contact with patients. The interaction with patients threatened their sense of ontological security (Giddens, 1991). Disconnection from dying and its bodily realities appeared to be a better option than confrontation with it from the point of view of extended family members and friends (Broom and Kirby, 2013).

Findings here show that a visibly altered body is still a matter of concern to terminally ill patients and thereby provide an alternative to accounts presented in Lawton's (2000) study, where physical appearance was downplayed. A reflection was also provided within the present chapter about the ways in which gender shapes and constrains terminally ill patients' experiences of a visibly altered body. I found that because of masculine and feminine norms physical appearance is more a matter of concern to

women than to men. The findings of the current study contradict those of Lawton (ibid), who argued that gendered differences are not noticeable amongst terminally ill patients. What became evident was that negative emotions related to having an altered physical appearance have a detrimental impact on the self-identity of terminally ill patients and that this impact could vary according to patient's gender.

These findings need to be interpreted in the light of Portuguese culture as it has been found to be a country characterized by strong societal gender differences (Aboim, 2010; Andreotti et al., 2001; Karin et al., 2001; Lopes, 2006; Moreno, 2006; Tavora, 2012). Women's roles in this country have been profoundly marked by traditional and reproductive domestic roles (ibid) which have led to the fact that their social value has been related to their physical selves and their evaluations of their bodies (Hurd Clarke, 2000). This is particularly true for older women (ibid), who are the main object of my study.

Having outlined the centrality of bodily appearance to the self-identity of patients who are very ill and at the end of life, I will now turn to a discussion of the importance of bodily autonomy, as it has been considered elsewhere (Lawton, 2000) to be a central aspect for the maintenance of one's sense of personhood.

Chapter Five

Making sense of a changed physical body: Why gender matters

5.1. Introduction

Theorizing in the field of death and dying has been dominated in the last decades by the sequestration debate - which argues that death has been sequestered from the public domain. This debate has been at the heart of Lawton's (2000) study, where it is said that dying people are sequestered within hospices as a result of the modern western intolerance of bodily deterioration and decay. The hospice 'served to impose order upon disorder through enclosing and containing the odours emitted from patients' disintegrating bodies within a bounded space' (Lawton, 1998: 134). The body's ultimate vulnerability is revealed and this is what makes the sequestration of dying so necessary (Ellis, 2010). Hospice patients tend to lose their capacity to maintain control over their physical boundaries and, at one and the same time, the ability to act according to their own wishes and intentions – i.e. their bodily autonomy (Lawton, 2000). This has been found by Lawton (*ibid*) to have a debasing impact on hospice patients' sense of self and identity.

Lawton (*ibid*) presented the experience of loss of bodily autonomy as largely undifferentiated. The ways in which gender norms might shape and constrain this experience remains unexplored. Lawton suggested a potential 'degenderisation' of hospice patients. She argued that along with the process of bodily deterioration and decay patients lose the capacity to do gender. Lawton draws upon a binary conception of gender in which gender is either lost or maintained (Broom and Cavenagh, 2010:

870). A more nuanced conception is needed. While male and female patients might encounter similar problems, their reactions could be highly differentiated due to masculine and feminine norms. Thus, I attempt to challenge Lawton's (ibid) thesis that gender differences are not marked amongst those who are very ill and at the end of life.

Portugal offers a particular context to study the embodied character of gender at end-of-life as it has been a country shaped by a traditional conception of what it is like to be a man and a woman (Andreotti et al., 2001; Karin et al., 2001; Lopes, 2006; Moreno, 2006). The social attitudes within Portuguese society tend to support traditional roles as for instance despite the increase of female employment in Portugal there has not been an increase in the participation of men in the domestic sphere. The bulk of domestic work still falls to women, which clearly shows a traditional gender division of labour in the home (Tavora, 2012). Women in Portugal are seen as nurturers and child-rearers and thus they have to combine full-employment with caring roles (Aboim, 2010).

The aim of this chapter is to understand: *In what ways does the loss of bodily autonomy affect the sense of self and identity of Portuguese terminally ill patients? Does it differ by gender?* The purpose here is to explore how the experience of loss of bodily autonomy at end of life is gendered and influenced by masculine and feminine norms. This chapter starts by examining how terminally ill patients deal with a lack of corporeal capacity for self-containment. Then it moves on to analyze how patients live with the loss of ability to act as the agent of their own embodied actions and intentions. It ends by discussing patients' attitudes and beliefs towards being physically dependent upon the help of others. These points are discussed in relation to masculine and feminine identity.

5.2. The lack of corporeal capacity for self-containment

It has been argued that because ‘the routine control of the body is integral to the very nature of agency and of being accepted (trusted) by others as competent’ it is ‘a fundamental means whereby a biography of self-identity is maintained’ (Giddens, 1991: 57-58). Despite the recognized importance of the routine control of the body to the maintenance of individuals’ self-identity, few studies have explored the ways in which the unboundedness of the body questions the integrity of self and identity for those who are very ill and at the end of life (Lawton, 2000). The extent to which the loss of bodily boundedness experienced by dying people is shaped and constrained by masculine and feminine norms also remains largely unknown. Thus, the present section aims to make a further contribution to the literature by acknowledging the impact that the loss of control over bodily boundaries has upon the self-identity of terminally ill patients, as well as to illustrate its gendered character.

The majority of the patients in this sample had bodies which Lawton (2000) would term unbounded as they have lost control over their physical boundaries. This would mean that the ‘fluids and matter normally contained within the patient’s body were leaked and emitted to the outside, often in an uncontrolled and ad hoc fashion’ (Lawton 1998: 127). Like the patients in Lawton’s (ibid) study, most patients in my study were likely to suffer from incontinence of urine and faeces and a few from weeping limbs and fungating wounds. The latter was found to be a problem for patients because of the smell released. For instance, a 65-year-old woman with a Merkel Cell carcinoma, who

had several ulcers, commented that she was concerned about their smell and the impact of this on other people:

The smell does not bother me. I am more concerned with other people.
I think that people may be disturbed by the smell.
(Brenda, terminally ill patient)

Drawing upon Douglas's (1966: 36) work, the smell emitted from a patient's body could be seen as a 'disorder' or a 'matter out of place'. The intolerance towards it could be understood as a 'pollution behavior', i.e. a reaction which rejects an idea that contradicts cherished classifications about cleanliness and order (ibid). This reaction is the product of a specific civilizing process, which involved the elaboration and internalization of a whole series of taboos regulating bodily functions and bodily exposure (Elias, 1994: 114). As odours cannot be easily contained they could escape and cross boundaries (Classen et al., 1994: 5). Indeed, because of its 'boundary-transgressing quality' the odours released from a patient's body could extend their own corporeality and intrude and seep into other spaces and, ultimately, other bodies (Twigg, 2000: 397).

For instance, Lawton (1998: 133) found that the odours released from patients' bodies not only precipitated their admission into the hospice, but also brought about their marginalisation within the hospice itself. She noted that the smell created a boundary between patients for whom the surfaces of the body had ruptured and broken down and others who had bounded bodies. Lawton observed that on several occasions hospice

staff transferred unbounded patients to side rooms in order to contain the odours emitted from their bodies within a specific space. As a way to maintain the integrity of their own selves the other participants in the hospice - patients and family members - avoided having contact with unbounded patients. This was so because they were afraid that their boundaries were breached by the corrosive effects of patient's disintegrating bodies (ibid: 134).

Unlike the patients in Lawton's (1998, 2000) study, the patients in this study for whom the surfaces of the body had ruptured and broken down were not transferred to side rooms and did not experience negative reactions from other participants within the hospice. The findings of the current study are also not in accord with the findings of Twigg's (2000) study, where it is said that what was most difficult for care workers to bear was the smell released from patients' bodies. Some staff members (five) in this sample directly stated that the odour released from patients' disintegrating bodies was not something they considered difficult to deal with. They made comments similar to those of a nurse:

It [the smell] does not bother me anymore. Honestly, we learn to disconnect from these kinds of things. I don't mean that I cannot smell it. But it's not relevant.

(Clara, nurse)

The odour released from patients' disintegrating body, unlike what happened in Lawton's (1998: 133) study, did not create a boundary around the patient, causing them to push others away. The smell was something more or less expected by palliative care

staff, in particular in cases where patients suffered from malignant wounds, as the following account given by a nurse indicated:

I noticed that for people who care [nurses and auxiliaries] it is an aspect [the smell] that they are more, I don't say prepared, but they understand that is something that is connected [with the process of dying]. It is more expected from people who have malignant wounds. People are confronted with that. Thus it is not so difficult to deal with for those who care for them.

(Chloe, nurse)

While the differences outlined here in relation to Lawton's (2000) study were mainly in relation to the perception of odours, I also found differences in terms of the strategies developed to deal with this. When I conducted the fieldwork the odour released from patients' bodies due to fungating tumors and/or to incontinence of urine and faeces was very weak and most of the time non-existent. The smell in the context studied, and in contrast to what happened in Lawton's (2000) hospice, was the typical antiseptic smell of a hospital setting. The staff here, and in contrast to what happened in Lawton's (ibid) study, did not burn aromatherapy oils around patients' beds to mask the odour. The strategies employed by the staff to avoid/combat the odour released from patients' disintegrating bodies were instead pharmacological strategies - e.g. medication - as well as hygienic strategies - e.g. the constant changing of diapers and the continuous application of dressings and bandages. For instance, when a patient contracted a bladder infection specific medication was given to him/her to control it and thereby his/her urine did not develop an offensive smell - in contrast to what happened in Lawton's (ibid)

study. What was most problematic in relation to incontinence was not the smell per se but the fact that it challenged a patient's status and thus represented a return to childhood as they had to use a diaper or other devices to control leakage, as the following comment made by a doctor shows:

I think it's very difficult for patients to accept that they need to use a diaper. Most of them feel that it's a return to their childhood. They don't accept it very well.

(Carmen, doctor)

In a similar way, Maderson (2005) in his study with people with limited or no bladder or bowel control found that they tended to be repositioned as child-like. The loss of control over leakage contradicts ideas of autonomous adulthood. Indeed one of the hallmarks of a child's passage from infancy to maturity is the ability to control bladder and bowel functions (Hockey and James, 1993: 85). For example, the wife of a 69-year-old man with prostate cancer pointed out that for her husband incontinence and the consequent use of diapers was a sign of decrepitude:

I: What did your husband say about the diaper?

Anastasia: 'Take this off me! Take this shit off! I don't want to use this!' When he was okay and we talked about my mother, as my mother is still alive. When she went to a nursing home she started to use diapers, and he said: 'She now uses diapers. Poor her. She is not well.' For him the diaper was terrible. For him a person who uses diapers is someone who is not well.

(Anastasia, wife)

Incontinence has been not only associated with decrepitude but with a loss of social competence (Mitteness and Barker, 1995). The loss of control over leakage leads to a loss of social competence in the sense that 'it makes visible what, according to cultural standards should be kept private in order to maintain the construction of humans as different and separate from one another' (Isaksen, 2002: 804). That is, incontinence appears to challenge the basic ontological principal within western culture that one should be able to put 'mind over matter' (Jervis, 2001: 96). Indeed it has been found elsewhere that in order to maintain full participation in social life incontinence is often made secret (Maderson, 2005; Mitteness and Barker, 1995). The findings of my study nevertheless contrast with those of previous studies, where it is said that people with limited or no bladder or bowel control tend to restrict their social participation (Brittain and Shaw, 2007; Herskovits and Mitness, 1994). Although I recognize that the loss of corporeal capacity for self-containment has had a detrimental impact on patients' self-identity, I did not find sufficient evidence to support the theory that these patients 'switched off and became disengaged from all events and relationships taking place around them' (Lawton, 2000:132) by virtue of their loss of ability to control leakage.

What became evident was that the loss of bodily closure was experienced by male and female patients in dissimilar ways. This was particularly notable in terms of how they deal with incontinence of both urine and faeces and the devices used to contain them. The two men who had to use a diaper and/or a catheter to control bowel and/or bladder leakage (the other three did not have to use these) asserted that this has been very difficult for them to accept. A 58-year-old man with prostate cancer demonstrated how

uncomfortable he felt about using a diaper by acknowledging that he had already asked to use a commode as an alternative to it, a request which was denied by palliative care staff:

Brad: I have a diaper.

I: How do you feel about it?

Brad: Well, it's a bit difficult. I used it earlier. They said: 'do it on the diaper'. Because they don't have commodes here. They are out of stock. They've been out of stock for a long time. I am quite surprised that in a house like this they are out of stock.

(Brad, terminally ill patient)

Brad was stoical and - like other patients in this study - struggled against the use of diapers. His reaction reflected masculine traits (Broom and Cavenagh, 2010) such as being tough, stoical and strong (Smith et al., 2007). It is worth mentioning that while it may be true that commodes were out of stock, at the time of my fieldwork I never saw any patient using or asking for a commode (with the exception of Brad), thus I would suggest that the explanation given by the staff was a strategy used by them to avoid Brad asking for a commode. It is important to acknowledge that it could be very difficult, and ultimately painful, for patients to use a commode once they have lost their physical dexterity as they were not able to support the weight of their body. The use of a commode could eventually damage the spine of patients who suffer from bone metastases. In addition to physically protecting patients from harm, the staff also avoided to use commodes to prevent episodes as recounted by Lawton (2000) in which terminally ill patients were found in a bed full of excreta and/or urine.

The stories recounted by some family members (five spouses and one daughter) confirmed that incontinence and the consequent use of devices to contain it challenged masculine norms. The hegemonic masculine script (Connell, 1995) places an expectation on men to be physically competent (Bennet, 2007) and thus it is understandable that they experienced feelings of anger, frustration and sadness about the use of diapers. Within this group of family members, two spouses indicated that the diaper was so stressful to their husbands that they often tried to remove it, as the following extract from the interview with the wife of a 69-year-old patient with prostate cancer demonstrates:

He didn't want to use the diaper. He tried to remove it. He once removed it and peed out of the diaper. Now he is more debilitated. But he still tries to remove it.

(Anastasia, wife)

Two spouses stated that for their husbands the use of a diaper did not seem to be appropriate, as the following excerpt from the interview with the wife of a 63-year-old patient with cancer of the esophagus shows:

He never wanted to do it in the diaper. This was something that was very difficult for him. (...) He thought that it was not right to do it in the diaper. He thought that he had to do it in the bathroom and not in the diaper.

(Alice, wife)

The traditional masculine characteristics of agency and strength (Cameron and Bernardes, 1998; Prentice and Carranza, 2002) make it easier to understand why male patients fight against incontinence and the use of devices to contain it. This contrasts to the attitudes of the women in this sample. The accounts given by two female patients who had to use a diaper (in a total of three) indicated a certain resignation towards it, after an initial period of discomfort. A 78-year-old woman with ovarian cancer asserted that, albeit at the beginning of her illness she was very sad about the fact that she had lost control of her bladder and bowel functions and thus needed to use diapers to contain leakage, she ended up accepting it:

Becky: I cannot go to the bathroom because I have lost my ability to control urine and faeces. I am totally incontinent.

I: How did you react to being incontinent and to the use of diapers?

Becky: Very sad, of course. But now I have accepted it.

(Becky, terminally ill patient)

The other female patient who had to use diapers to control leakage indicated a certain relief about it. This 69-year-old woman told me that the use of a diaper avoided her going to the toilet alone and thereby risking getting injured. Indeed she recounted an episode while she was at home where she fell on her bathroom floor and spent the whole night there:

Bridget: During my last days at home I started to use diapers. Because I wanted to pee at night. I couldn't hold the urine at night.

I: How did you react? Did it bother you?

Bridget: No! They [home nursing auxiliaries] told me that it would be better for me to use diapers. That I would be more relaxed. It was on the days that were very cold. That it was better because I would be more relaxed. That I did not have to get up at night. I went to the toilet alone. But some days before I came (to the unit) I went alone but I fell and I was unconscious for a while because everyone there was sleeping. I called them but they didn't hear me. My son saw me on the floor in the morning.

(Bridget, terminally ill patient)

The accounts provided by some family members (i.e. two husbands, one daughter, one sister-in-law and one cousin) confirmed that it was less difficult for female patients to accept the use of diapers and they try to accept their condition to the best of their ability. Within this group of family members, three indicated that their loved ones understood their need to use diapers and conformed to their use, as the following quotation from the interview with the daughter of a 64-year-old woman with breast cancer clearly indicates:

She understood that it [the use of diapers] is the only way. There is no other way. We tried to use a commode but she couldn't do it.

(April, daughter)

The accounts given by a few family members (two) suggested that their loved ones' reactions towards incontinence and the consequent use of diapers made them a good patient – 'one who is passively compliant with societal norms, family wishes or health providers' recommendations' (Proulx and Jacelon, 2004: 117). The comment made by a

husband of an 80-year-old woman with non-Hodgkin's lymphoma illustrates this point well:

I: How did your wife react towards the use of diapers?

Alan: Well, she did not show anything. I thought she would have a bad reaction or not like it. She never showed. I think she has been a good patient because she never complained about it.

(Alan, husband)

The account above is very interesting in that it is reminiscent of Li and Arber's (2006) notion of virtuous patient - 'one who managed to preserve cheerfulness and serenity of mind in spite of injuries or dying' (ibid: 37). Women's apparent passivity and acceptance of incontinence and the consequent use of diapers could be related to feminine norms of nurturance and sensitivity to the needs of others (Prentice and Carranza, 2002; Hurd Clarke and Bennet, 2013b). These women could be denying their own feelings and needs as they were concerned with the needs and feelings of significant others (Exley and Letherby, 2001). Women, unlike men, have been found to be primarily responsible for working with emotions - whether their own or others (James, 1989). In the face of such a 'biographically disrupted event' (Bury, 1992) these women's reactions could be interpreted as an attempt to keep things 'normal' (Exley and Letherby, 2001). This could also be related to gendered assumptions about incontinence (Peake and Maderson, 2003). Although urination and defecation are not a gendered function, it has been found elsewhere that women tend to associate the loss of control over leakage with gender and to some degree to internalize incontinence as

normal. The experience of incontinence has been encompassed within the rubric of ‘womanly inheritance’ (Peake et al., 1999: 283). There is ‘a broadly common coding of the female body as a body which leaks, which bleeds, which is at the mercy of hormonal and reproductive functions’ (Grosz, 1994: 204).

These gender differences in terms of the loss of continence and the use of devices to contain bowel and bladder leakage were also made apparent in the accounts given by palliative care staff. Indeed a few (four) members of staff confirmed that male patients found this particularly difficult to accept. Their accounts were akin to those of a doctor:

We have to explain to the patient that he can no longer go to the bathroom. I think this is more difficult for men. Men are less able to deal with this...to deal with dependency...not being able to go to the bathroom...of not being able to pee...to do it at home...to use a diaper.

(Castle, doctor)

This issue was even more magnified in the comment of a volunteer, who stated that women are more used too than men to use what he calls ‘accessories’ due to for instance their reproductive cycle and thus the use of a diaper may not be such a big issue for them as it may be for men. He spoke about a male patient who was bed-bound but wanted to get up and go to the bathroom as he did not want to use the diaper, despite the staff advising him to do so:

Women for other reasons are more used to 'accessories'. Men are not. This of course influences. Men feel that there is an extra weight. And say: what the hell! I am not used to this! I don't think there are any patients who don't feel this. A patient says to me: 'I want to go to the bathroom.' [volunteer:] 'But you can't get up. You have a diaper please do it on the diaper.' [patient:] 'But I don't want to do it. The nurse told me the same. But I don't want to do it.' This thing of not wanting is maybe because it may be very disturbing.

(Chandler, volunteer)

When asked about why incontinence and the consequent use of diapers were more difficult for men than for women, a few members of staff (two) answered that this was due to one's privacy as well as to men's sense of masculinity and their advanced age. A nurse asserted:

Because it is related to privacy. To the physical part. To what it means to be a man. To exposing oneself to others. Also we cannot forget that most of our carers are women. Young women. And for some people, in particular those in their 70s and 80s, it is difficult to deal with the loss of control over leakages and the use of a diaper.

(Ciara, nurse)

The account above is very interesting in that it draws attention to the ways in which the gendered meanings of the body create obstacles to incontinence and toilet assistance. The masculine traits of control and invulnerability (Cameron and Bernardes, 1998; Prentice and Carranza, 2002) could make intimate caregiving for male patients more difficult in comparison to their female counterparts. The traditional feminine characteristics of acceptance and passivity (ibid) could make it easier for female patients

(Wong, 2005). Findings here, then, did not lend support to Lawton's (2000) argument that gendered differences are not marked amongst terminally ill patients, namely in terms of how they live and deal with their unbounded dying bodies. There is a subtle and important relation between the ways in which male and female patients reacted to their lack of capacity for self-containment and feminine and masculine norms. I thus suggest that gender provides an important starting point for explaining the ways in which the loss of bodily boundedness impacts upon patients' sense of self and identity.

Also, unlike Lawton (*ibid*), I did not find evidence that 'patients with unbounded bodies have lost one of the criteria for personhood by virtue of their lacking the corporeal capacity for self-containment' (2000: 142). Indeed, Lawton's theory 'of the impossibility of being a person whilst having a body without boundaries' (1998: 131) was not made apparent in my interviews and fieldwork observations. Whilst I recognize that Lawton (2000) was right in arguing that the process of bodily deterioration and decay experienced by terminally ill patients must be situated 'within the wider context of an increasingly sanitized western culture' (Broom and Cavenagh, 2010: 875) I suggest that a more comprehensive understanding of the phenomenon is needed. This should be situated in an understanding that hospice/palliative care may be able to offer a valued alternative to the care of the unbounded dying body - as will be discussed in Chapter Six.

5.3. The loss of bodily ability to act as an autonomous agent

It has been found elsewhere (Lawton, 2000) that as dying patients deteriorate they not only tend to lose control over their physical boundaries, but also the ability to perform tasks for themselves. Yet, little work has been done in understanding the ways in which the loss of ability to act as an autonomous agent impacts upon the self-identity of terminally ill patients. The limited research available on patients' loss of ability to act as the agent of their embodied actions and intentions has focused on the experiences of older and chronically ill people and not those of dying people per se and has shown that this experience is marked by gender differences, as men and women are likely to experience their physical limitations differently (Hurd Clarke and Bennet, 2013a, 2013b; Smith et al., 2007; Canham, 2009). Thus, attention will be paid in this section to how terminally ill patients live and deal with the loss of ability to act as an autonomous agent, in particular to the ways in which gender actually shapes and constrains this experience.

Like the patients in Lawton's (2000) study, most of the patients in this study had lost the ability to act as autonomous agents. Almost all patients suffered from advanced cancer and as the illness deteriorated they had lost their bodily strength and physical dexterity. They also suffered from intense weakness and lethargy. Some had developed bone metastases or a spinal cord compression and thereby had become bed-bound or wheelchair bound. The loss of bodily mobility was something that most patients had experienced even in the earlier stages of the illness. What became evident in my findings was that the loss of ability to act as an autonomous agent led patients (three men) to leave their jobs and this was understood by them as something very difficult to

live and deal with. A 58-year-old man with prostate cancer, who had become bed-bound, put it simply:

Brad: I had to leave my job [after the diagnosis of his illness].

I: Why? Was it due to the problem in your leg [he had lost the use of one of his legs]?

Brad: Yes.

I: How did you deal with it? Was it difficult for you?

Brad: Yes, it was a bit difficult for me. In fact, it is still difficult for me.

(Brad, terminally ill patient)

The importance that men placed on work and the difficulty for them of dealing with this loss was also evident in the discourse of a 45-year-old man with colon cancer and liver metastases. This man, due to an infection after a surgical procedure, had lost the extremity of most of his fingers, as well as suffering from lethargy as a result of the progression of the illness, and as a result was no longer able to carry on his profession as a dentist:

Brian: What I miss most is working.

I: What was your job?

Brian: I am a dentist. I say I am because I will continue to be until I am able to do it.

I: What have the doctors told you about this? They've told you that you will be able to work soon?

Brian: Nothing. They said that I cannot work.

(...)

I: Is it a concern to you not being able to work?

Brian: Yes, it is a big concern to me.

I: Was your job important to you?

Brian: Yes, very much.

I: Was it something that fulfilled you?

Brian: Yes, it was the most important thing that I had. In terms of what I've done physically it was very important.

(Brian, terminally ill patient)

The salience of work experience was evident in the way Brian described himself. This man spoke about his profession as a dentist as something that was part and parcel of his identity. Work was so meaningful for this respondent that one might speculate that in the long-term his loss of ability to persist in his profession as a dentist will affect his sense of personal worth. This matter became apparent in the account provided by a 52-year-old man with esophageal cancer, who suffered from lethargy and due to chemotherapy had lost the sensitivity in most of his fingers. He stressed that because of his illness he had been forced to leave his work:

Ben: The problem is that I've always been independent. I've always been independent from others.

I: Is it very painful for you?

Ben: Yes, it cost me a lot. To see that in seven or eight months my life has stopped. It has been cancelled. I don't have the chance to be with people, to be within the system.

I: What do you miss most?

Ben: I miss my work a lot. Because when I was working I was always happy. For me the work was always fine. If something went wrong I went for a coffee and when I came back everything was okay again.

I: Did you feel fulfilled by your job?

Ben: Yes, without doubt. It's very painful for me to see that in seven or eight months I lost my ability to work.

(...)

Ben: In the morning I went to work and had the chance to stop and go for a coffee. Then at lunch I always met with a friend to have lunch with him. At dinner time it was the same thing. 'When are you going to dinner?' They knew that I was alone. 'Well, let's go for dinner.' I went with them. I drove the truck and went with them.

(Ben, terminally ill patient)

This man associated his loss of ability to work with a loss of independence. He was no longer able to act as an autonomous agent. In the interview I conducted with him, as well as with other men, it became evident that work was an important source of personal satisfaction. He spoke about his work as being meaningful and positive. Work was also described as a source of social bonds. Ben had no family and very few friends or social contacts besides those from work. The findings presented here are in accord with those of Moss and Moss (2007), who in their study with men in long-term care found that work was an important source of interpersonal bonds as the ties with co-workers were central to their social world. As with the men in Moss and Moss's (ibid) study, the memory of work was fresh in the minds of the men I interviewed even though they had been retired for many years. This was the case for a 59-year-old man with liver cancer, whose work memories were very positive and who expressed regret at having had to leave his job:

Bob: I worked in a graphics company.

I: Did you like your job?

Bob: I loved my job! I worked from 1966 until I retired.

I: How did you feel about leaving your job?

Bob: I felt sorry. I tried to make an arrangement with my boss for working some hours even though I was retired. He agreed but it did not work out well. I felt really sorry.

(Bob, terminally ill patient)

The loss of ability to work undermined men's ability to achieve and adhere to hegemonic masculinity (Hurd Clarke and Bennet, 2013a), which has been associated with autonomy, control and invulnerability (Prentice and Carranza, 2002). Thus, it is understandable that the theme of work was more prominent in the discourses of men than of the women interviewed for this study. What my findings suggested was that work is still a matter of importance for the men who are dying as this is seen as a marker of their male identity. This convincingly shows the interplay of bodily autonomy and gender identity and thus contradicts theories (Lawton, 2000) that have suggested that gender is not an important matter for the study of dying and its bodily realities. The fact that the loss of bodily capacity might contradict masculine norms could also explain why male patients expressed feelings of anger, sadness and loss of self-esteem due to their loss of ability to perform tasks for themselves, as indicated by some (seven) family members. The account provided by the wife of a 72-year-old man with lung cancer helps to illustrate the way in which male patients may feel useless due to their loss of bodily autonomy and how this might lead them to question their self-worth:

His reaction was very bad. 'Why am I still here? Why am I here? Why has God not taken me? I am not doing anything here. I am a burden.' He was a very independent person. So it was complicated. He was very active. He had a motorcycle and a bicycle. Last summer I felt very sorry for him because he was constantly talking about the beach. He loved to swim and go to the beach. He felt a lot of sadness when there were beautiful days and he could not go out.

(Andrea, wife)

The loss of bodily capacity challenged taken-for-granted assumptions, which could lead to a sense of personal disruption (Bury, 1982). The comment of a wife of a 66-year-old man with brain cancer illustrates this point well by acknowledging how sad her husband felt about losing his ability to drive:

He felt very sad. 'Why can't I get up? I want to go to the farm but I am not able to go. I cannot drive.' [patient] 'I can drive you if you want and we can go there.' [relative] 'No. I cannot sunbathe. What am I going to do there?' [patient]

(Antonia, wife)

While the loss of bodily capacity symbolized by the loss of their ability to drive was strongly felt by the men in this study it prompted different reactions from their perspective. For example, an 82-year-old man who had had a stroke became very angry about his loss of bodily capacity and fought to have his driver's license back, as his wife explained:

There were periods when he was very angry. He cried at that time. He had some crises. The stroke had damaged his vision. He could only see from his right side. He couldn't see from his left side. He thought he could see. He never accepted. They took his driver's license and he fought a lot. He argued with his doctor: 'I can drive!'. It was a war!

(Adrianna, wife)

This man's battle to retain his driver's license could be related to his fear of experiencing an erosion of his masculinity (Broom and Cavenagh, 2010: 872; Canham, 2009; Smith et al., 2007). The loss of independence represented by the loss of ability to drive contradicted masculine norms of physical power, self-reliance and toughness (Hurd Clarke and Bennet, 2013a; Prentice and Carranza, 2002; Cameron and Bernardes, 1998). The accounts provided by a few female patients (two) and family members (one) suggested that women were more likely to 'come to terms' with their loss of ability to act as autonomous agents than men. For example, when asked about how her relative felt in relation to the loss of bodily mobility, the daughter of a 66-year-old woman with tongue cancer asserted:

She is getting used to it. She is getting used to it.

(Amanda, daughter)

Also, a 78 and a 72-year-old woman with ovarian cancer spoken about their loss of bodily mobility as follows:

How can we react to a situation like this? Of course I reacted badly. I didn't react well. I reacted badly. But there is nothing else we can do.

(Becky, terminally ill patient)

Bella: I was upset! I was upset!

I: Did you feel anger towards it?

Bella: No. I didn't feel anger. I was upset not angry. I was not angry. I never get angry. I accepted the disease. But I felt upset.

(Bella, terminally ill patient)

In contrast to the men in this study, the women did not express feelings of anger against their loss of bodily capacity, although in a similar way they experienced feelings of sadness. Unlike the men, the women did not fight against their condition but made an increased effort to integrate it as best as they could. Their accounts reflected a need for acceptance (Hurd Clarke and Bennet, 2013a). An interesting finding was that although male and female patients were likely to present different attitudes towards their loss of bodily ability both male and female patients experienced feelings of social isolation due to their inability to move and act. These feelings were made apparent in an account provided by a 69-year-old woman with cancer of the esophagus, who expressed her sadness about the fact that because of her loss of bodily mobility she had become bed-bound and as a result isolated from her loved ones:

Bridget: I have not been able to walk for more than a year. Last year at Christmas I sat at the table but with the help of a wheelchair. This year I was not able to go. It was in my home. Normally I went to the house of my daughter. But this year I stayed at home. It was a very sad Christmas.

I: Did you stay in bed?

Bridget: Yes, I stayed in my bed.

I: How did you react to it?

Bridget: Very badly. Very badly. Because I was not able to sit at the table. It was the first time that this had happened.

I: How did you react to being in bed?

Bridget: I thought why has this happened to me? It's sad. In my room at home I have a window and I was always looking at the people in the street.

(Bridget, terminally ill patient)

These feelings of social isolation were not exclusive to patients who were bed-bound, or to home-bound patients, as this account given by a 52-year-old patient with cancer of the esophagus shows:

I used to be outside. To drive the car here and there. Now I feel I am completely stuck. It seems that I am in a prison.

(...)

Because I cannot go out. I cannot chat with other people. If we go for a coffee we say good morning to the person that comes in. We sit, drink a coffee. We see people. It's a distraction to the brain. Here we always see the same people.

(Ben, terminally ill patient)

The statement above is also very interesting in that it shows that the loss of bodily mobility made social contacts and connections difficult to sustain (Nicholson et al., 2012). The inability to move and act and the disappearance of social contacts made this man feel like a prisoner in the palliative care unit. This feeling has been similarly reported by older people who had become physically dependent and house-bound (Hammarstrom and Torres, 2010). The social isolation experienced by this man was increased by his lack of opportunity to frequent important public spaces for him such as cafes. Local cafes, for instance, have been found to be privileged spaces for masculine socialization in Portugal (Vale de Almeida, 2004). Thus, one might speculate that for this man the frequenting of cafes was a 'way of doing gender'. That is, of 'being

masculine' (Ribeiro et al., 2000: 312). The idea that certain public spaces are more important for men than for women and vice-versa was confirmed in the accounts provided by other patients. For instance, while a 72-year-old woman with ovarian cancer outlined the frequenting of cafes, she also spoke about visiting local shops and acknowledged how these were important places for her by expressing her sadness at no longer been able to go there:

Today what I miss most is not being able to go onto the street. To be able to walk. I lived in a neighborhood in Lisbon. I knew a lot of people in the shops. I went to the shops. I spoke with them. I sat there for a while. Sometimes they even had a chair for me. I sat there chatting with them. Well, I had a life, I don't mean a social life, as I don't call this social. But I had a good coexistence. I went to the cafe to drink my coffee and eat my cake. I went to the shop to buy a ring. Now I only have this (a ring) and it is constantly falling off. I gave everything to my daughter and daughter-in-law. But I mean buy a ring or other things. I bought things that I liked. I went to the supermarket. I mean I had my life. Now I have nothing.

(Bella, terminally ill patient)

The findings presented here lead me to conclude that men and women react very differently to the loss of ability to move and act. Thus, my study adds to the theorizing of the loss of bodily autonomy and the role of gender and in doing so contradicts Lawton's (2000) thesis that gender differences are not marked amongst terminally ill patients. Having outlined this, I now turn to a detailed consideration about how being physically dependent may undermine the sense of self and identity of men and women in dissimilar ways.

5.4. Being physically dependent

As terminally ill patients lose their physical capacity to ‘move’ and ‘act’ they are likely to become physically dependent upon others, particularly for the provision of daily living activities such as toileting and bathing. Although the evidence that terminally ill patients’ loss of bodily autonomy inevitably leads to an unreciprocated dependence upon others little work has been done on how dying people understand this experience. This paucity of research is evident in the interplay between gender and physical dependency at the time of dying. The bodily experience of terminally ill patients has been described as largely undifferentiated and thereby no significant gender differences have been so far acknowledged (Lawton, 2000). Hence, the aim of this section is to provide a better understanding of how terminally ill patients actually experience their physical dependence. Attention will be paid to gender differences amongst the patients in this sample.

As described previously, I found that the provision of intimate care, whether toileting or bathing, was difficult for men to accept. The discomfort felt by male patients in relation to the provision of intimate care by the staff was described by a son of an 85-year-old man with rectal cancer in the following way:

I: In terms of the provision of bodily care, is there any aspect that is more difficult for your father?

Aaron: Yes. The bath. The observation of his intimate parts. The provision of intimate care.

(Aaron, son)

This statement is very interesting in that it shows how the provision of intimate care by staff was a vulnerable moment for patients. They had to undress and expose their intimate body parts (Isaksen, 2002) and nakedness has long been associated with intimacy, namely with sexual intimacy (Twigg, 1997). ‘The link between nakedness and closeness is both a direct one, in that nakedness permits actual physical touch and closeness, and a metaphorical one, in that to be naked is to divest oneself of protection and disguise’ (Twigg, 2000: 46). While some (three out of five) of the men in this study directly stated that the provision of intimacy was a difficult moment for them, they stressed that this was even more problematic when it was provided by members of the opposite sex. A 78-year-old man with lung cancer spoke about how uncomfortable he felt about it as follows:

The bath is very difficult for me. I am not used to it. I’m not comfortable. This is even more difficult when it is provided by female nurses.

(Billy, terminally ill patient)

This man’s discomfort could be partly explained by the sexual taboo ‘which defines any contact, whether opposite sex or same sex, with another person’s naked or near-naked body outside of conjugal relations, as immoral or at least sexual’ (Wong, 2005: 384). However this does not explain why it was more difficult for the men in this study than for the women to accept the provision of intimate care by palliative care staff. Masculine and feminine norms appear to be at the heart of these differences. The

provision of intimate care challenges the masculine ideals of self-reliance, strength and independence (Bennet, 2007). In contrast to male patients' accounts, the accounts given by female patients (five) suggested a degree of acceptance towards the provision of intimate care. For example, a 65-year-old woman with Merkel Cell carcinoma pointed out that albeit at the beginning it was awkward she considered that the provision of intimate care by staff was no longer a problem for her whether it was delivered by men or women:

I got used to that [i.e. the provision of intimate care by staff members]. It was very difficult for me at the beginning because I've never been in a hospital before. I am an old fat lady and this was very difficult for me, especially when they were male nurses. When they were men it was more difficult for me. Now I am used to it. It no longer makes a difference if they are men or women.

(Brenda, terminally ill patient)

This woman, like the older people in Twigg's (2000: 59) study on bathing, had internalized a sense of her body as not being pleasant and thereby as something that would be distasteful to have to manage. However her fears eroded as time passed. The accounts provided by a few family members (three) confirmed that after an initial period of discomfort female patients were likely to get used to the provision of intimate care by others - whether by palliative care staff or by family members. For instance, a daughter of a 66-year-old woman with tongue cancer recognized how uncomfortable her mother was when she had given her bath for the first time although this feeling had now passed:

I felt that she was embarrassed the first time I had to give her a bath.
But then she got used to it.

(Amanda, daughter)

A comment made by the sister-in-law of a 78-year-old woman with ovary cancer shows how women have fewer concerns in relation to being naked in front of others. This respondent suggested that her relative 'came to terms' with the fact of being cared for by others:

Angela: I gave her a bath while she was at home. I helped her. I was afraid that she would fall. I was afraid that she would fall so I helped her. She is not shy. She is able to be naked in front of others.

I: How did your sister-in-law react to being dependent upon others for her basic needs?

Angela: Well, she did not have another option. She got used to it.

(Angela, sister-in-law)

The greater emotional and bodily expressivity of women's lives - through motherhood and nurturance - could also explain the gender differences found in terms of the acceptability of the provision of intimate care. Women could understand the touch of the body as less problematic compared to men due to such processes (Twigg, 1999). The touch of the body could also be associated with a less dominant position (ibid, 1997; Whitcher and Fisher, 1979) and thus contravene the image of the 'ideal man' - one who is not weak and vulnerable (Bernardes and Lima, 2010). The gendered

character of body care (Twigg et al., 2011) was extended to those who provide intimate care within the family as it became evident that it was less difficult for patients to accept been cared for by the women in their lives. For example, a psychologist asserted that the provision of intimate care was a more stressful situation for patients when it was delivered by sons:

When sons have to care for their mothers it's complicated. It's very difficult for a mother to be dependent upon her son. It's easier when the carer is a daughter even if she needs to care for her father. Issues concerning intimacy are less difficult to deal with. I am talking in terms of basic hygiene such as a shower. It's more difficult for a mother to be cared for by her son.

(Candy, psychologist)

The expectation placed on women that they should be responsible for the care of their family members could explain why it was less difficult for patients to be cared for by their daughters or other female relatives. Within the family women have traditionally been responsible for the care of babies and young children, and thus, not surprisingly, they continue to do it for their elderly and dying parents (Breheny and Stephens, 2012; Donorfio and Sheehan, 2001; Read and Wuest, 2007; Twigg, 2000). This is particularly relevant to the Portuguese context, where women retain the bulk of domestic work (Aboim, 2010; Tavora, 2012). Indeed, a number of studies have indicated that in Portugal the care of children and older people is strongly delegated to women, despite the higher rates of female employment (Andreotti et al., 2001; Karin et al., 2001; Lopes, 2006; Moreno, 2006).

Although it was less difficult for some patients to be cared for by their daughters or by other female relatives, they did not expect that the women in their lives would care for them. Indeed all of the women in this sample and one man expressed concerns of being a burden on their loved ones. For instance, a 65-year-old woman with Merkel Cell carcinoma stated that she did not expect the support of her two daughters in terms of her bodily care as she knew they were too busy with problems in their own lives and she did not want to be a burden to them. Before her admission into the in-patient unit this woman had been living in her daughter's home however her condition began to deteriorate and she was no longer able to stay there as she needed constant care. Her daughter had two young children and was not able to leave her work to take care of her mother. Her other daughter lived far away - on a Portuguese island - and thus was also not able to care for her:

I always thought that I could not count on my daughters. We can count on them to give us support when we need. But it is a mistake to think that they will care for us. Only if they are at home. If they are working I know how it is. Because they work all day. They have their children. (...) In terms of this (caring) I knew that I could not count on my children. They are working. One does not live here. The other works and she has her life.

(Brenda, terminally ill patient)

This woman also commented during the interview I held with her that for most of her life she had cared for others, namely for her husband, who died one month after she had been diagnosed with cancer. Her memories of providing care to her relatives were very

present in her mind, as well the emotional suffering she had experienced due to this. Her comments illustrate this point well: ‘Hope you never know what it is like not sleeping for one and a half years. I was a nurse 24 hours per day. I gave him baths. I cut his beard. I cut his hair. I changed his diaper. I cleaned his ass. I fed him. It was very complicated’. This woman’s previous experience of caring for her dying father and husband framed her understanding of caring and explains why she did not wish to be cared for by her daughters. Her position reflected a somewhat ‘gendered sensitivity to the notion of dependence’ (Chatoo and Ahmad, 2008: 557). ‘The choices and boundaries related to notions of legitimate help with personal care’, as Chatoo and Ahmad (ibid: 557) have pointed out, ‘implicate gendered sensitivities as part of the larger biographical and socio-cultural context within which meanings of caring and relatedness are nested’.

Also, this suggests that patients are able to exercise choice by recognizing that their adult children do not have responsibility over their care and thereby deciding who can be involved in the provision of intimate care (ibid). This indeed led patients to accept being admitted into the palliative care unit, as the account provided by a 72-year-old patient with ovary cancer, who did not want to be a burden on her adult children, indicates:

I: Are you afraid to be a burden?

Bella: No because I am here [palliative care unit]. I always said that I did not want to be a burden on my children. I am here now.

(Bella, terminally ill patient)

The excerpt above is very interesting in that it suggests that the need for others help does not necessarily lead to a loss of agency, unlike what has been described by Lawton (2000). The admission into the in-patient unit was for this group of respondents a solution to release the burden on their families. Indeed hospice admission has been marked by the need to reduce the burden placed by dying patients on their families (Broom and Cavenagh, 2011). These women and men indicated ‘other-oriented’ attitudes (Hurd Clarke, 2013b; Arber et al., 2008) towards the need for help from their family, in the sense that they were concerned about being a burden on their loved ones. The wish to not be a burden expressed by the women in this study could be related to expected feminine qualities that privileged nurturance, selflessness and sensitivity to the needs of others (Prentice and Carranza, 2002).

In contrast, two men adopted a ‘self-oriented’ attitude (Hurd Clarke, 2013b; Arber et al., 2008) towards their need for family help in the sense that they did not express significant concerns about being a burden to their loved ones. A 58-year-old man with prostate cancer put it simply:

Brad: No [not afraid to be a burden]. I am not afraid to ask for their
(family) help. They are good to me. And I cooperate with them.
(Brad, terminally ill patient)

The other two men in this sample did not have family or any contact with them so there was no chance for them to feel a burden. A 59-year-old man with liver cancer pointed out:

No [not afraid to be a burden]. Not at all. Not at all. I never had a mother or a father. They never wanted to know about me. I was raised by two persons who had already passed away. They were my 'true' mother and grandmother. My father has had four sons, and my mother two, but we never got along well.

(Bob, terminally ill patient)

Although none of the patients interviewed reported a wish to die sooner, unlike in Lawton's (2000) study, the accounts provided by a few members of staff (three) suggested that this may be so when patients strongly believe that they are a burden on their family, as the following quotation from an interview with a nurse shows:

There are patients who think about it [death as a blessing]. Because they are dependent on others. Because they feel they are a burden on their families. It is a huge suffering.

(Chloe, nurse)

The detrimental impact that the need of others' help and the feelings of being a burden had upon patients' self-worth was spoken about by some members of staff (nine), whose accounts were akin to those of this psychologist:

I think patients always go through a very difficult phase in which they question their self-worth. They feel that they are a burden to others. They feel that they are no longer functional. They feel that they are no longer able to control their bodies. Of course this has a tremendous impact on their self-worth.

(Chantal, psychologist)

Despite the strong impact as mentioned above that the need of being dependent on the help of others might have on a patient's self-worth, none of them described themselves as objects or were described in this way by family members or members of staff. This contrasts with Lawton's (2000) findings, where it was said that as patients' physical weakness and degree of dependency increased so too did their 'object-like' self-conceptions. Unlike Lawton, I did not find evidence suggesting that patients' loss of bodily autonomy and thus their unreciprocated dependence upon others led to a debasement of their personhood. Although depending on others led to a diminishment of patients' self-worth, as well as to the fear of being a burden, particularly on their loved ones, it did not lead to a loss of personhood. What is particularly revealing in my findings is that gender shapes and constrains the experience of being physically dependent on others.

5.5. Conclusion

In this chapter I have focused on the ways in which terminally ill patients live with and deal with the loss of bodily autonomy. Bodily autonomy is defined as the ability to act according to one's own wishes and intentions and the capacity to maintain control over one's physical boundaries (Lawton, 2000: 165). The aim here was to provide a better understanding of the experience of loss of bodily autonomy and to show how cultural factors such as gender might intersect with this experience. Thus, I offer a counter position to theories (Lawton, 2000) that have suggested a 'degenderisation' of terminally ill patients.

What became apparent was that male and female patients experienced their loss of corporeal capacity for self-containment differently. The men's reaction - namely their will to fight - towards the loss of continence and the consequent use of devices to contain it reflected masculine traits such as being tough, stoic and strong (Bennet, 2007; Smith et al., 2007). Women's reaction was less negative compared to those of men: they made an increased effort to come to terms with the loss of corporeal capacity for self-containment. They showed a need for acceptance - a common feminine trait (Cameron and Bernardes, 1998; Prentice and Carranza, 2002). Their reaction could also be interpreted as an attempt to protect their loved ones from feelings of distress (Exley and Letherby, 2001) as it has been found elsewhere that nurturance and sensitivity to the needs of others are important feminine traits (Hurd Clarke and Bennet, 2013b). Thus, the findings outlined suggest that there are subtle and important differences in terms of how men and women react towards the loss of bodily closure prior to impending potential death.

The men and women in this sample also presented dissimilar reactions towards their loss of ability to act as autonomous agents. The loss of ability to move and act contravened masculine norms of physical power, self-reliance and toughness (Cameron and Bernardes, 1998; Prentice and Carranza, 2002) and this might explain why men presented more negative reactions to it than women. Whereas men tend to become angry and sad, women made efforts to integrate as best they could their physical condition. This aligns with the traditional female and masculine roles where women are passive and men are agentic (ibid). These gender differences were not so prominent in terms of how the loss of bodily mobility contributed to feelings of social isolation. Both male and female patients experienced these feelings. This was understandable as bodily mobility underlines the process by which social contacts and connections are made and sustained (Lawton, 2000). What my findings add to the theorizing of the loss of ability to act as an autonomous agent is the role of gender by demonstrating that men and women have different attitudes and feelings towards their loss of ability to move and act.

The findings outlined suggest that being physically dependent is marked by gender differences as this was something more problematic to male patients than to their female counterparts. The image of the ideal man - one who is not weak and vulnerable - is in direct contrast with the image of the ill and dependent man (Bernardes and Lima, 2010). Increased dependence on others challenged masculine norms of autonomy and control (Prentice and Carranza, 2002). Gender also helps to explain why female patients were more concerned about being a burden on their loved ones than most of their male counterparts. All of the women indicated 'other-oriented attitudes', whereas some of the

men expressed 'self-oriented attitudes' towards the need for others' help, particularly from family members (Hurd Clarke et al., 2013b; Arber et al., 2008). Indeed female patients showed a clear 'sensitivity to the notion of dependency' which was marked to some extent by the memories of what it is like to care for dying relatives (Chattoo and Ahmad, 2008). The feelings of being a burden were nevertheless, unlike what happened in Lawton's (2000) study, not accompanied by object-like self-conceptions. Thus, I did not find evidence that supports Lawton's (ibid: 52) argument that patients' loss of bodily autonomy and their unreciprocated dependence on others led to a debasement of their personhood.

I agree with Broom and Cavenagh's argument that Lawton 'provided a rather linear representation of the body during a hospice death' (2010: 874). Like the patients in Broom and Cavenagh's (ibid) study, the patients in my study presented highly differentiated symptoms (i.e. incontinence of urine and faeces, weeping limbs, fungating tumours, major pain, bodily paralysis, functional and cognitive impairment). Lawton's findings appeared to be very much related to the context of the hospice where she conducted fieldwork. Lawton acknowledged that 'the manager's concern with the efficiency and cost-effectiveness of the hospice led to increasing pressure being placed upon staff to discharge patients at the earliest possible opportunity and to refill the beds immediately' (2000: 22). This inevitably led to the highest priority for admission to the hospice being accorded to patients requiring symptom control, who had bodies which Lawton referred to as unbounded. As the staff were expected to discharge patients after a one or two week period of stay those who were more likely to remain and die at the hospice where unsurprisingly those for whom the boundaries of their bodies could not

be successfully reinstated. Lawton's work offers a particular point of view of a hospice, which took place according to her own words 'during a particularly notable period of transition and change' (ibid: 22).

To answer the research question posed at the beginning of this chapter - *in what ways does the loss of bodily autonomy affect the sense of self and identity of terminally ill patients? Does it differ by gender?* - I argue that the loss of bodily autonomy is gendered in the sense that men and women experience it in dissimilar ways. One should bear in mind that Portugal, unlike the UK, is strongly marked by societal gender differences (Aboim, 2010; Andreotti et al., 2001; Karin et al., 2001; Lopes, 2006; Moreno, 2006; Tavora, 2012) and that my findings need to be situated within this context. The findings presented here ultimately show what it is like to be a man or a woman in Portugal who has lost the corporeal capacity for self-containment, as well as the ability to act as an autonomous agent and as a result has become physically dependent on others.

Chapter Six

The meaning and experience of a dignified death in light of the process of bodily deterioration and decay

6.1. Introduction

The philosophy and practice of the modern hospice and palliative care movement advocates that caring for a dying person necessarily involves respectful and compassionate care (Clark and Seymour, 1999). Indeed palliative care professionals are trained to believe that through person-centred and holistic care they will be able to address the physical, psychological, social and spiritual needs of terminally ill patients (McNamara et al., 1994). However, the ideal of a ‘dignified death’ - or what has also been called a ‘good death’ - proposed by the proponents of the modern hospice and palliative care movement has been questioned. The ‘good death’ has been described by the founders of the hospice and palliative care movement as one that involves a ‘pain free death; death at home, surrounded by family and friends; death as personal growth; death according to personal experience; an aware death, in which personal conflicts and unfinished business are resolved; and open acknowledgment of the imminence of death’ (Clark, 2002: 907).

A few studies have shown that in the face of the complex bodily realities of dying palliative care professionals are likely to give prominence to the medical responses to pain and symptom management as it offers a more certain response to these realities than social, psychological and spiritual counseling (McNamara, 2004). Lawton (2000), for instance, has offered a powerful critique to hospice and palliative care by

acknowledging that suffering was being exclusively seen as the experience of physical pain. Lawton further argued that the proponents of the modern hospice and palliative care movement have promoted a ‘disembodied conception of the dying process’. Lawton, by highlighting the debasing impact that the bodily realities of dying has upon a patient’s sense of self, questioned if it is in fact possible to ‘die with dignity’ (ibid: 179). It seemed that this debasing impact might be related to one’s concept of personhood. Indeed Lawton claimed that ‘personhood has become particularly entwined with the body and bodily capacity’ (ibid: 175). While this might be true for some who conform to a ‘rhetoric of individuality’, for others who feel closer to a ‘familistic ethos’ and thereby tend to give primacy to the role of relationships in life this might not be so. Portugal, as a country characterized by a familistic nature (Andreotti et al, 2001; Dykstra and Fokkema, 2010; Jurado-Guerrero and Naldini, 1996; Lopes, 2006; Reher, 1998; Tavora, 2012), offers a suitable context to explore this issue. There is a need to understand if in a familistic context such as that of modern Portugal the bodily realities of dying lead to a fundamental loss of dignity in the sense that patients might feel that their value as a person is threatened. Thus, this chapter asks the question: *in light of the bodily realities of dying is a dignified death something that Portuguese terminally ill patients can realistically hope for?*

The present chapter starts with a section that aims to understand if palliative sedation was in fact used by palliative care staff to benefit terminally ill patients, and the extent to which this practice enables the provision of a dignified death. The preferences around death and the disclosure of dying are examined in the second section. The physical, psychological, social and spiritual dimensions of the care given to terminally ill patients

are broadly discussed in the third section. In the last section the extent to which the concept of dignity shapes the philosophy and practice of palliative care in Portugal is illuminated and, in doing so, attention is paid to the meaning of personhood at the end of life.

6.2. The loss of consciousness

Findings from the current study show that terminally ill patients not only become increasingly dependent (as described in Chapter Five), but they also experience a loss of consciousness. These findings concur with previous reported research that has indicated that when patients are approaching death they tend to move in and out of coma (Armstrong-Coster, 2004) and to lose awareness of themselves and their environment (Lawton, 2000). Despite the fact that the loss of consciousness experienced by patients may be a direct consequence of the biological changes associated with the dying process, it has been shown elsewhere (Lawton, 2000; McNamara, 2001; Seymour, 2007) that more often than not it is induced by hospice staff through palliative sedation.

Lawton observed that when patients drifted in and out of consciousness and exhibited somewhat 'psychotic behaviour' hospice staff were likely to sedate them heavily, thereby rendering them 'docile' (2000: 119). Thus, Lawton argued that sedation was not performed primarily to reinforce the hospice's ideology of a good death. On the contrary, she claimed that sedation was used by hospice staff to maintain the 'sentimental order of the ward' (ibid). I question if this is so in the context studied and

the benefits of palliative sedation for patients in the light of dying and its bodily realities. The aim of this section is to extend the understanding of palliative sedation and the ideal of a dignified death.

The use of palliative sedation was understood by several staff members (twelve) as a practice primarily used for the benefit of the patient who was very agitated and confused, as well as in pain or with uncontrolled symptoms, and then for the family, who were distressed due to the physical and emotional suffering experienced by their loved one's impending potential death. For instance, a physiotherapist commented that although sedation may help families who feel anxious due to a patient's agitation and/or confusion it is not primarily used with this intention, but instead to help the patient to be calmer and to die in his/her own time without distress:

I think sedation is beneficial to a patient when he needs to be calmer. We will not sedate a patient because family members are concerned because he is agitated. But we will sedate the patient if he is very agitated and then we will calm him and thereby his family. This has to be measured by the team. It is not only one person who decides that we will sedate this patient. Of course not! Well it could be the case that the patient asks to be sedated at the end to be calmer. We do not practice euthanasia. But we help the person to be calmer. To be peaceful. That he/she could die in his own time without suffering. This is really important.

(Catherine, physiotherapist)

This was even more magnified in a comment made by a head-nurse, who stressed contended the relationship between palliative sedation and the provision of a dignified

death, as it may help the patient to die in a peaceful way as well as allowing the family to experience a peaceful death:

I think it's an ally. There are times when sedation is essential for the patient and the family. With sedation we are able to provide patients with a dignified death. This is because we reduce their suffering. I don't know if sometimes we worry more about the patient that is dying or more about the family that remains. The suffering of those who are living cannot be taken away. The inevitability of death is always present. Maybe it's important to help those who stay to see some dignity. To see that the patient is no longer in delirium. To see that the patient is no longer in pain. Sedation is often used when the suffering of the soul is huge. Maybe sedation is essential to calm everyone, especially families.

(Charlotte, head-nurse)

Palliative sedation has been described elsewhere (McNamara, 2001; Seymour, 2007) by health care professionals as an effective means for relieving patients' physical and emotional suffering. For instance, Seale (2009, 2010) noted that doctors' decisions to sedate patients were more often than not a response to intractable pain, uncontrolled symptoms and/ or psychological distress. Delirium, followed by dyspnea and major pain, has been found to be the most frequent reason for sedation in the palliative care context in Portugal (Gonçalves et al., 2003; 2012) and elsewhere (Faisinger et al., 2000). This is in accord with the findings of the current study. Indeed most of the patients who were sedated were likely to suffer from delirium and a few suffered from major pain.

For some patients, and like those in Lawton's (2000) study, when they were sedated they end up losing their ability to interact with significant others. The story of Bianca, a 71-year-old woman with a chordoma (i.e. rare skin cancer), illustrates this point well. Following her admission, Bianca became very agitated and confused. She suffered from delirium. Bianca was heavily sedated by the staff so she could be more peaceful and as a result she was no longer able to interact with her loved ones. Bianca's oldest son (Alphonso) reported this concern to a nurse (Carl) who was on duty when he came to visit his mother for the third time after she had been admitted into the in-patient unit by acknowledging that it was very difficult for him to accept that his mother was no longer able to recognize him:

When I arrived at the palliative care facility this morning Alphonso and Carl were talking near Bianca's room. Alphonso was very disturbed and Carl tried to calm him down. Bianca's son said to Carl: 'For me it's very difficult to see my mother in this state. She cannot even recognize me. I think she is worse since she has been here. Before she came here she was able to recognize me. Now she can't'. Carl responded: 'I understand. We had to give her some tranquilizers because she was very agitated and confused, as you know. She is calmer now. I know she is not able to communicate but you can still be with her. Hearing is the last thing you lose. So she can still hear you. We will do our best to help your mother.'

(Extract from field notes)

Lawton's (2000) findings that patients' sense of personhood was erased by palliative sedation in the sense that they lose their ability to act is to a certain extent similar to my findings. Bianca's story is an example of how patients could lose aspects of their personhood when they become heavily sedated. However Lawton's (ibid) argument that

sedation imposes a social death on the patient appears to be from my point of view an extreme position in the sense that although patients were sedated their family members continually tried to interact with them. This was particularly evident in my fieldwork observations. The patients (five) who were not sedated but due to their illness had lost the awareness of themselves and their environment were not abandoned by their family members as they visited them regularly (a more detailed consideration about the interaction established between family members and patients will be provided in the next chapter). Unlike the staff in Lawton's (2000) and McNamara's (2001) studies, the staff here did not treat these patients as if they were already dead. An example of this is the fact that the staff continuously spoke about patients in team meetings and expressed a strong will to relieve their physical, psychological, social and spiritual suffering. Also, when the staff were in their presence they tried to engage in a conversation with them and explained the procedures they were doing, whether changing a diaper or giving medication.

The findings of this study also indicate that palliative sedation was to a certain extent supportive of a 'good death'. The case of Beatrice, a 68-year-old patient with an occult tumor (i.e. a tumour that was hidden or so small that it couldn't be found), helps to illustrate this issue. Four months after her admission at the in-patient unit Beatrice asked the nurse about her prognosis. The nurse said that the best thing to do was to question the doctor about it. Two days on, a nurse (Ciara) during the team meeting indicated that Beatrice had had a frank and open conversation with the doctor about her illness and thus was aware of her impending potential death:

Today in the team meeting Ciara [nurse] told other staff members that the doctor had told Beatrice that she was suffering from cancer and that she was likely to die. The doctor had explained to Beatrice that all members of staff would help her during the dying process and all her needs and wishes would be addressed. Ciara stressed that Beatrice broke down in tears and said that she already suspected this was so. Ciara also stated that later on that night Beatrice had told a nurse that she was very upset with the fact that everybody knew of her terminal illness except herself.

(Extract from field notes)

On the following day, Beatrice confronted her husband (Albert) and he said that he already knew it but did not have the courage to tell her. Albert was afraid of the negative consequences that the disclosure of the diagnosis could have on the wellbeing of his wife. In a conversation with her husband, Beatrice stressed that she wished that after her death Albert should look for another woman to marry so that he would not be alone. Albert and Beatrice were married for almost forty years. Albert was very disturbed with Beatrice's comment and reported his feelings to the psychologist. Beatrice was very concerned about her husband and became very anxious about it. She became agitated and confused in the weeks that followed. Beatrice's existential suffering was evident. The psychologist of the unit tried to talk with Beatrice about her worries but had no success. The staff also provided spiritual support but Beatrice was so delirious that she was not able to have a proper conversation. The staff were unable to address the existential aspects of Beatrice's suffering. Albert's wish was that his wife would not suffer. In the interview I held with Albert he stressed: 'There is no cure. There is no chance of her getting better. So my only wish is that she does not suffer.' After four weeks the staff decided to sedate Beatrice so she could be calmer. The

decision to sedate Beatrice was also a difficult one for staff. For instance, on the day that Beatrice has been sedated I found a nurse crying in the staff room. When I asked the head nurse about what happened she told me that it was painful for this nurse to watch Beatrice's suffering and to acknowledge that Beatrice's existential suffering was so intense that they had to sedate her to minimize it. She died two weeks after being sedated. The staff by sedating Beatrice helped her to die calmly. Also, this gave to staff and family members an outward appearance of Beatrice having reconciled herself at the time of dying and this has been found to be an important element of the 'good death' (Kubler-Ross, 1969).

Thus, it could be argued that because palliative sedation helped terminally ill patients to die during a deep sleep, it reinforced the ideology of a 'good death' advocated by the proponents of the modern hospice and palliative care movement (Seymour, 2007). Findings here contrast with those of Lawton, who argued that the 'hospice ideology of a good death' requires the location of 'docile bodies' within communal space (2000: 121). Unlike the patients in Lawton's study (*ibid*), the patients in this study were not sedated heavily to render them 'docile' and thereby to maintain what Strauss et al. (1982) have described as the 'sentimental order of the ward'. I am not saying that palliative sedation was not beneficial to the organization itself as it helped the staff to do their work more effectively and to provide to patients a dignified death. Instead, in line with the extant research concerning hospice and palliative care (Faisinger et al., 2000; Gonçalves et al., 2003; 2012; Rietjens et al., 2007), I argue that the primary reason for the use of palliative sedation was to benefit patients who were experiencing extreme suffering. The staff in the current study were aware that sometimes they were not able to minimize

patients' suffering (in particular their existential suffering). This most of the time was not related with the bodily realities of dying per se but with patients' life circumstances. Hence, in these situations palliative sedation appeared to be the best option as it enabled patients to die calmly and with dignity.

Having outlined this, I will now provide a more detailed consideration of the preferences around death.

6.3. Preferences around death and disclosure of dying

The notion of a death with dignity, or what has been commonly referred to as a 'good death', appears to be relevant here since it informs the philosophy and practice of hospice and palliative care. The 'good death' ideal as proposed by the founders of the modern hospice and palliative care movement necessarily involves an open awareness of death and acknowledgment of the potential imminence of dying (Clark, 2002). As this ideal is based on a 'revivalist script' which emphasizes individual control and choice it might be more relevant to Anglophone countries where there is a concern to maintain control over projects of self-identity (Seale, 1995; Seale et al., 1997; Seale, 1998) than to non-Anglophone countries (Gordon and Paci, 1991; Long and Long, 1982; Long, 2004) where 'there is both greater trust in authority and willingness to allow others (such as family members) to care for the self' (Seale, 1998: 5). 'The desire for open awareness of dying is related to a dominant ethos of individualism' (Seale et al., 1997: 477) and thus it would not be a surprise if in countries with a strong familistic

nature like Portugal (Andreotti et al, 2001; Dykstra and Fokkema, 2010; Jurado-Guerrero and Naldini, 1996; Lopes, 2006; Reher, 1998; Tavora, 2012) the approach to death reflected the dominant ethos of familism. The aim of this section is to explore the extent to which the ‘revivalist’ discourse on death (Walter, 1994; Seale, 1998) shapes and constrains the ‘good death’ ideal in the context studied.

Asking terminally ill patients about the meaning and definition of a good death seemed to me to be unethical as they were in a vulnerable position and this question could arouse in them problematic feelings. Moreover, by bringing to the fore such a question patients could become suspicious about their condition, and as I will further discuss most of them were not aware of their prognosis. Thus, I only asked this question to family members and palliative care professionals about their perceptions of what might be a good death for the patient. I assumed here that family members and palliative care professionals would be acting in the best interest of the patient (Elinkenberg et al., 2004), although their ideas of a good death may sometimes not coincide with patients’ own (Payne et al., 1996b).

A good death was described by almost half of the family members (eight out of twenty) as one without suffering. Their comments were similar to those of the sister-in-law of a 78-year-old woman with ovary cancer, when they were asked about what they thought might be a good death for their loved ones:

With the least suffering possible. I think it is the only thing we can ask for. Health is only a miracle. So with the least suffering possible.
(Angela, sister-in-law)

For some (six) family members a good death for their loved one was one in which they would die suddenly, as the following excerpt from the interview with a wife of a 66-year-old man with brain cancer shows:

A sudden death. A death without knowing. A death without suffering.
Is the one (death) that I wish for my husband.

(Antonia, wife)

A few (four) family members expressed the wish for their loved one to die while asleep.

The son of an 85-year-old man put it this way:

When my father is asleep. The candle reaches the end. He is asleep
and then...

(Aaron, son)

A good death was here defined by family members as one in which the patient dies suddenly, while asleep and without suffering. The preference for a sudden death in one's sleep could to a certain extent be explained by the desire to avoid distress (Aleksandrona et al., 2013). There are some parallels between the good death definitions presented by family members and those presented by staff members. A death without suffering was also popular with a few members of staff. Indeed three staff members described a good death as one in which the patient dies free of pain and without any apparent distress. They made comments similar to those of a

physiotherapist, who also recognized the importance of saying goodbye to loved ones and stated that she believed that so far they had been able to provide a good death to patients:

A good death is one in which the person dies free of pain. One in which the person dies without distress. One in which the person says goodbye to other people. I think this is very important. I think we have been able to provide this to people.

(Chris, physiotherapist)

In addition to being without pain and any apparent distress, a few (four) members of staff described a good death as one which is accompanied by loved ones. For example a nurse stated:

A good death for me is to be pain free. To be without uncontrolled symptoms. To be as peaceful as possible. To be surrounded by family. We have some patients that due to some circumstances die alone. I don't think any of us would like to die alone.

(Cecilia, nurse)

More than half of the members of palliative care staff (eleven) described a good death as one in which the patient dies in peace, calmly and quietly. Their comments were akin to those of a spiritual and religious counselor, who also acknowledged a sense of preparedness towards dying:

Feel peaceful. Feel quiet. Feel calm. Feel ready. This is dying well.
(Charlie, spiritual and religious counselor)

Like the extant research that has explored the features of a good death for hospice staff (Payne et al., 1996b; Lawton, 2000; McNamara et al., 1994), a good death was considered by the staff in this study to be one in which the patient died free of pain, without distress, peacefully, quietly and with family support. A good death was also described by a few (two) members of staff as one that the patient wants. A head-nurse put it this way:

A good death is one where the person decided right up to the end what he wants. Even if this means that the person will suffer until the end. A good death for me is not only one in which the patient is pain free. It is the one that the patient wants. It is the one that he chose.
(Charlotte, head-nurse)

This element of choice has also been described by hospice staff in a study by McNamara (2004), where it was said that patients should take responsibility for the way in which they will die. Although the ideal of personal choice has been considered by a few (two) members of staff to be a central element of a good death - which is in accord with the model proposed by the proponents of the modern hospice and palliative care movement (ibid) - I found that this situation was rather more complex, in the sense that most patients were not aware of their impending potential death. Indeed there is a controversy between the ideal of personal choice and an open awareness of dying which

leads me to suggest that the good death in the context studied did not conform to the ‘revivalist’ script. The most common situation in this study, as the accounts provided by half of the members of staff (ten) suggested, was one where at the time of admission to the palliative care unit patients were not informed about the potential imminence of death and thereby they were likely to experience what Glaser and Strauss (1965) have described as a ‘context of closed awareness’. The members of staff made comments similar to those of a head-nurse:

From our experience patients arrive here without knowing the prognosis. The majority of them. I think around 90% of patients arrive here without having any idea about the prognosis. Most of them arrive here without knowing the disease context. Without knowing the prognosis. Many patients think they are here to do physiotherapy. Because someone has told them that they will have a special treatment here. That they will recover better here. Only a small number of patients are informed. I don’t say well informed but informed. I think around 30% know that they have a serious illness. The prognosis only a few know.

(Ciara, head-nurse)

Three members of staff indicated that the major reason for patients not being informed about the prognosis was that doctors at the hospital were more likely to discuss this matter with the family than with the patient and in doing so instigated what has been referred to as a ‘conspiracy of silence’, in the sense that the truth was hidden from patients, as the following statement from an interview with a psychologist suggests:

I think there are many gaps in terms of communication. We often talk about the ‘conspiracy of silence’ from the point of view of families who do not share with the patient the prognosis but we don’t talk about the conspiracy of silence that is made by health care professionals. Specifically by health care professionals related with curative medicine. What we have found is that there are gaps in terms of communication. The problem is given to families by these health care professionals. What we realize is that most of the time these health care professionals tell the family but don’t tell the patient and they expect that the family will tell the patient the prognosis.

(Chantal, psychologist)

This statement is also very interesting in that it confirms Seale’s (1998) theory that the rival script to that of revivalism draws upon a willingness to trust in authority and respect tradition. Empirical research conducted in Portugal has found that the possibility of causing harm to patients (Gonçalves and Castro, 2001), alongside the belief that the communication of a terminal illness is the responsibility of the family (Cardoso, 2009) were the main reasons why doctors did not disclose their prognosis to patients. This latter point shows the familistic nature of Portuguese culture in the sense that the care of the self is given to the family (Seale, 1998). Three members of staff contended that family members knew about the prognosis but made considerable efforts to hide this information from the patient, as the following excerpt from an interview with a volunteer indicates:

One of the principles of palliative care is not to hide anything from the patient. This also implies that the family knows about what is happening. And there are families who say: ‘oh please do not say anything to my father! Don’t say anything to my grandfather! Please don’t speak about this [the prognosis]!’

(Chandler, volunteer)

This so called ‘conspiracy of silence’ was confirmed by some family members (six), who indicated that their loved ones did not know their prognosis and the likelihood of their death. They made comments akin to those of the daughter of an 87-year-old man with bladder cancer:

If my father knows he does not say it. We never told him about it. He is sick. He’s sick. He knows he is sick. But no one told him what [his prognosis was] specifically. We prefer it this way. Because I know my father and I know if he knew it he would get worse, it will be very painful for him. We don’t talk much about it. He’s sick. We have told him that he is here to get better. When he gets better he will go home. Basically it’s this that he knows. He does not know more.

(Adele, daughter)

This ‘conspiracy of silence’ was nevertheless not interpreted as an act of abandonment or denial - unlike what happen in the ‘revivalist’ discourse - but as a strategy for family members to express care and concern (Seale, 1998: 178). For instance, when questioned about why her family had never informed her father that he was likely to die Adele indicated that they were afraid of the negative consequences this could have on his well-being:

Adele: I thought about telling him [about the prognosis]. If it was up to me he would know. But it is not me who decides.

I: Did you decide altogether [with her other 2 sisters]?

Adele: Yes.

I: Why did you make this choice?

Adele: Because we are afraid that he would get depressed. I believe this would be so. My sister thinks this way and I agree with her. He was always a very independent person. He was never dependent on others. I think if he knew about his terminal illness he would give up.

(Adele, daughter)

This respondent feared that her father might lose his will to live if he knew about his terminal condition. Maintaining her father's hope was a central concern for this daughter. We may also speculate that the maintenance of patients' hope was another major reason as to why other family members did not want to disclose the prognosis to their loved ones. Gordon and Paci (2001), in their study carried out in Italy - a country which, like Portugal, has a strong familistic culture - found that the non-disclosure of a terminal illness was more often than not understood by family members as a 'moral duty' in the sense that it avoids the dying person's social death by instilling hope. Not telling was seen by the family members in Gordon and Paci's (ibid) study as a way to help their loved ones, namely to support them through a terrible life event. Also, by instilling hope family members were enabling patients to continue living life as normally as possible. The desire for normalization is in this light seen as a form of coping as it minimizes the effects of the potential imminence of death on the patient's identity (Bury, 1991: 460).

Findings indicated that a discourse illuminating uncertainty and hope (Beillin, 1981; Miyaffi, 1993; Mamo, 1999; Timmermans, 1994) was frequently employed by the staff in their interactions with patients and family members. This was for instance evident in the meeting held between some members of the team, Bruce and his relatives to discuss

Bruce's clinical condition. Bruce, aged 57, had been diagnosed with non-Hodgkin's lymphoma. Because he had brain metastases he suffered from periods of mental confusion. He had lost his ability to walk and to move from place to place he had to use a wheelchair. His wife had died twenty years earlier from breast cancer. Bruce had no children and his support was his brother and his two sisters, who were all present during the meeting. The doctor began the meeting asking Bruce about how he felt and the impression that he had about the unit. After 10 minutes, a trainee doctor came to collect Bruce saying that he had a clinical appointment. When Bruce left the room the doctor explained that the patient was very confused so he would not understand the purpose of the meeting and thus it was best for him not to be present. The doctor started the conversation with Bruce's relatives by asking them about their expectations of the illness:

'What are your expectations about your brother's illness?' Carmen [doctor] asked. His younger sister responded: 'We don't know. Do you think it is going to kill him?' Carmen said: 'I wish I could say no. I wish I could say that he will last a long time.' His sister broke down in tears: 'My only wish is that my brother does not suffer'.

(Extract from field notes)

The above extract suggests that the truth was kept from the patient. The doctor gave vague information about the prognosis to family members. The accounts provided by seven members of staff suggested that some patients were likely to experience a form of conditional awareness (McNamara, 2004) in their communication with health care professionals and family members in the sense that the disclosure of the prognosis took

place over a period of time (Field and Copp, 1999). A head-nurse articulated this as follows:

Our strategy is that the patient should be informed about what he would like to know. This is our strategy. We inform the family that we do not lie and that we would like to address the patient's needs. What often happens is that we tell little by little. The patient ends up making his own path and questioning some things directly. Then he ends up knowing about it [the prognosis]. There are many protocols of communication but here we use the Buckman protocol [a six step protocol for breaking bad news]. There are others which can be used. There are many ways to do it. Here we try to work on this issue [the disclosure of the prognosis].

(Ciara, nurse-chief)

The accounts provided by five family members suggested that a few patients were in fact informed about the prognosis and thereby knew about their impending potential death. This suggests that certain patients were likely to experience what Glaser and Strauss (1965) called an 'open awareness context'. The following extract from an interview with the wife of a 58-year-old man diagnosed as having colon cancer illustrates this point well:

I: What has the doctor said about his illness?

Addison: The doctor said that he had cancer. He said in a very clear way that he had cancer. That nothing more could be done to cure him. That they could only help to improve his time and quality of life. Nothing else.

I: And was your husband informed about the prognosis?

Addison: Everything happened in his presence.

I: How does your husband deal with it?

Addison: On the day that they told him it was as if the world had fallen down. As expected he reacted badly. He was scared. It was a surprise for us. Then it was the anger. He didn't understand why. Why this was happening to him.

(Addison, wife)

The following account provided by a 72-year-old woman with ovary cancer confirmed that she experienced an 'open awareness context' as she stated that her doctor had disclosed her terminal prognosis. This woman felt that her body was deteriorating and this signified to her that her death was close:

Bella: I feel that I am walking down the hill.

I: Why do you feel that way?

Bella: I am losing my leg muscles, my arm muscles. I have many difficulties turning in bed. I have difficulties turning from one side to another.

I: Have you talked about this with your doctor or with your relatives?

Bella: I have spoken with the doctor. But there's nothing to be done. There is nothing to do.

(Bella, terminally ill patient)

The body was indeed a symbol/marker of the proximity to death even for the patients who were not clearly informed about their terminal prognosis and thereby were likely to experience what Glaser and Strauss (1965) call a 'suspected awareness context'. A 78-year-old woman with ovary cancer stressed that although the doctors had told her that she would recover she knew that this was not so because she felt that her body was deteriorating:

Becky: I feel worse.

I: What has the doctor told you?

Becky: The doctor has told me that I will recover, but of course I will not recover. I know because the symptoms I have [i.e. major pain, faecal and urinary incontinence, and body paralysis] are getting worse.

(Becky, terminally ill patient)

Despite the fact that these two patients knew about their impending potential death, they did not discuss it openly during the interview I held with them. This was similarly reported by staff members at team meetings. Drawing upon Exley and Letherby's (2001) work, it could be argued that the decision made by patients not to discuss their terminal illness with others was no more than a strategy they employed to protect themselves. Indeed by avoiding discussing their illness terminally ill patients were able to maintain a 'normal' identity and a 'normal' interaction with others (Long and Long, 1982; Gordon, 1990). The patients in the current study did not appear to be interested in fulfilling the script of an heroic death, in which the dying person bravely faces and openly discusses his/her impending potential death (Seale, 1995: 608). Seale's argument that "open-awareness and acknowledgement of dying is a script particularly suited to the conditions of late modernity" (ibid: 611) is not in accord with my findings. Indeed the project of self-awareness does not seem to be a central preoccupation for the patients in this sample. The alternative script provided by Seale (ibid), which highlights the centrality of lack of awareness to the maintenance of hope, appears to be better suited to the Portuguese reality.

As with all organizational entities, hospice/palliative care is bound by culture and social expectations (Broom, 2012) and thereby it is shaped and constrained by the values of

the society in which it is based. Findings suggest that the practices of silence around the potential imminence of dying in Portugal need to be located within a larger cultural narrative which Gordon and Paci (1997) have referred to as ‘social embeddedness’. That is, ‘a narrative of social unity and hierarchy of protection from or adaptation to the inevitable necessities of life, in part by using narrative itself to construct a sense of group protection’ (ibid: 1433). This could be explained by Catholicism’s subsidiary principal - which Portuguese society is based upon - that family members should protect each other (Tavora, 2012). The ‘social embeddedness narrative’ (Gordon and Paci, 1997) provides a relational framework for dying well in Portugal and thereby offers an alternative to cultural scripts around a good death prominent in the UK which calls for an open awareness of death and acknowledgment of the potential imminence of dying (Clark, 2002). What became evident in my study was that the meaning of dying well within hospice/palliative care might vary according to cultural and social expectations.

In the current section the preferences around death and disclosure of dying which informed the philosophy of palliative care in the context studied were analyzed. In the next section the notion of total pain that informs the practice of the care given to terminally ill patients will be examined.

6.4. The notion of total pain and palliative care practice

The proponents of the modern hospice and palliative care movement advocated that in order to die well patients should have their physical, psychological, social and spiritual suffering reduced (McNamara et al., 1994). The movement has however been criticized for prioritizing the physical care of patients and the medical responses to suffering and death (McNamara, 2004). The voices of those involved in the care of the dying person have not been sufficiently heard and thus there is a need to make these voices heard in order to understand if the psychological, social and spiritual components of the supposedly person-centred holistic approach of palliative care (ibid) are in fact being neglected. The aim of the present section is to remedy this gap and to provide an alternative lens for understanding palliative care practice. As most of the patients I interviewed did not have sufficient knowledge about the meaning and significance of palliative care, findings presented here are based mostly on the accounts provided by family members and health care professionals.

When asked about the importance they give to the management of pain and the control of symptoms more than half of family members (eleven out of twenty) indicated that this was a priority for them and one of the most important aspects of palliative care practice. They made comments akin to those of a son of an 85-year-old man with rectal cancer, who expressed his satisfaction with the competency of the members of the palliative care team and the increasing effort developed by them to help his father and minimize his pain:

I: Is the control of pain and the management of symptoms something that you consider to be important?

Aaron: It is very important! My father has many pains. The pain is terrible in this phase. I don't know if you have heard of cases like this but the pain is terrible. Here they minimise this. They did not remove it completely... How can I say this? They put it [the pain] to sleep.

I: Do you think here they give some comfort to your father?

Aaron: Yes indeed. They gave him comfort. The treatment here in terms of comfort from the pain is wonderful. My father is not alone here. When he is in pain he rings the bell. Obviously he is not alone. He rings the bell. The staff may not be available immediately because they are with another patient but they know what is going on. Here the staff are very competent. I have to mention this because it is true. The doctors, the nurses, the care workers are all great people. When they are available they come to my father and help him. They give him what they have to give. For my father the pain is terrible. When he is in pain he asks everything, he even asks to go away [to die].

(Aaron, son)

This was even more magnified in the comment made by a husband of a 67-year-old woman with an occult tumor and bone metastases, who openly criticized the care given to her wife while she was at the hospital:

There is a difference from the day to the night. There [at the hospital] her arms were always shaking. Here they control it. They control her pain. Of course sometimes she has some pain. They have to change her because she is in that position. But it is not the same thing as when she was there [at the hospital]. It is nothing like what happened there. I don't want to criticize the hospital. Maybe here they are more specialized in this type of treatment, in people with these kinds of diseases. When I went to the hospital I was always anxious. Because I didn't know how I would find her. I was always anxious. I feel peaceful here. Because I know I will find her more or less well. I know that the doctors and the nurses here will do their best to relieve her suffering. They will take care of her until she dies.

(Albert, husband)

These findings are to a certain extent similar to the findings of McNamara and Rosenwax's (2007) study, where physical pain was described by bereaved relatives as something that was quite problematic for patients at the time of death. For more than half of the family members (thirteen) palliative care was an effective means to relieve patients' physical suffering, in line with what has been described by Broom and Cavenagh (2011), it enabled the regaining of a form of control over the bodily realities of dying. Thomas et al. (2004) found that concerns about the management of pain and symptom control were likely to influence patients' preference to place their final care in the hands of palliative care professionals. The view of palliative care expressed above by some family members as a means of taking control was to a certain extent shared by a few patients. Indeed four patients reported that they had less pain since they had been admitted to the palliative care unit. They made statements like those of a 78-year-old man with lung cancer:

I: Is the control of pain and symptoms something that you consider to be important?

Billy: Yes, it is.

I: Do you have pain now?

Billy: At home I had a lot. Since I am here I feel much better.

(Billy, patient)

Thus, in accordance with previous reported research (Broom and Cavenagh, 2010; 2011), it seems that for some patients the management of pain and the control of

symptoms was one of the most positive aspects of being at the palliative care unit. A few family members (three) indicated that the management of pain and the control of symptoms was the major reason for their loved one being admitted into the palliative care unit. For instance, the daughter of a 65-year-old woman with breast cancer and an osteosarcoma (i.e. a type of bone cancer) reported that she was unable to provide effective management of pain and symptom control at home in comparison to what happened in the palliative care unit and this had precipitated her mother's admission into the unit:

I: Is the control of pain and symptoms something that you consider to be important?

April: Yes. Sure. If not she [her mother] would be at home. If the staff have some difficulties in terms of giving her the right medication, and we are talking about a lot of people, you can imagine me at home alone. Because she said no to me and didn't take it. Now here she listens to people every day saying that she must take the pills so she accepted it. She accepted in the name of comfort.

(April, daughter)

Broom and Cavenagh's (2011) argument that palliative care offers to terminally ill patients and their families a sense of control over the bodily realities of dying is in accord with the findings of the current study. Indeed the accounts provided by almost half of the members of staff (eight) confirms that the management of pain and symptom control was one of the major reasons for patients being admitted into the palliative care unit, as the following extract from an interview with a spiritual and religious counsellor shows:

Patients usually come to the unit because they have uncontrolled symptoms and suffer from major pain. Major pain and uncontrolled symptoms are indeed the main reasons.

(Capri, spiritual and religious counsellor)

Like the staff in James's (1992) and McNamara's (2004) studies, most of the staff in the current study were likely to give prominence to the medical responses to pain and to uncontrolled symptoms. Indeed, more than half of the members of staff (thirteen) mentioned that the management of pain and symptom control was a top priority as they believed that without it it was not possible to work on the other aspects of care. They made comments akin to those of a nurse:

I think it's crucial that pain is controlled so we can have another type of intervention. It's like a pyramid. I don't want to prioritize what is most important in palliative care but symptom control is very important. If the symptoms are not controlled and the patient is in pain, we cannot work on the psychological and social aspects. We cannot work with the family. Relationships can be compromised. We cannot work on the other aspects if the symptoms are not controlled.

(Carl, nurse)

The staff believed that through effective pain control and symptom management terminally ill patients would be able to enjoy their last moments, without having to be concerned with the symptoms or other bodily processes they were experiencing. My fieldwork observations revealed that the staff continually re-evaluated patients' symptoms and whenever needed took measures to control them. This was particularly

evident when a patient's death was close and certain symptoms such as breathlessness and delirium tended to escalate. In addition to pain control and symptom management, the staff were also likely to pay attention to other dimensions of care. Indeed, almost half of the members of staff (nine out of twenty) highlighted the importance of the psychological, social and spiritual aspects of the care provided to terminally ill patients, as the following extract from an interview with a spiritual and religious counsellor suggests:

Not only older people but also younger people are in profoundly suffering. It is the separation of family. It is the job they have lost. The life projects that they will not end. It is the question: what have I done to deserve this? Why has this happened to me? The feelings of guilt that they sometimes have because they have managed their life badly. People who smoked or drank a lot. They question: Am I here because I have indulged in this behavior? We have to work on this. Then there are people who only see the bad things they have done in life. We have to help them to value all the good things that happened in their lives.

(Capri, spiritual and religious counsellor)

A nurse put it more strongly by arguing that one of the things which differentiates palliative care from other medical specialties is the importance given to the psychological, social and spiritual aspects:

Palliative care has to go beyond the control of symptoms. It has to be concerned with all the psychological questions. With people's suffering. With the family. The meaning that the person can give to this moment. How they can integrate this in their life. I think this is one of the best things about this kind of care. I don't believe that symptom control happens in hospitals as does here. They are very far

from this type of care. Especially concerning the psychological questions. All the questions around death and life. Of people saying goodbye. This I have found only here. I haven't found it anywhere else. I think this is the best aspect of this type of care.

(Claire, nurse)

A few (five) members of staff expressed a strong belief about the relationship between the physical and the psychological, social and spiritual aspects of care as according to them one aspect inevitably influences the other and vice-versa. They made comments similar to those of a head-nurse:

All the areas: the physical, psychological, spiritual; all these dimensions of the person need to have the same priority. Some dimensions are not more important than others. Because they all interact with each other. A person who is suffering spiritually is someone who will have more uncontrolled symptoms. The opposite is also true. A person who is in pain probably cannot have a good spiritual journey. I think one thing influences the other and vice versa.

(Charlotte, head-nurse)

In contrast to Lawton (2000), I did not find that the staff proposed a close and seemingly exclusive relationship between physical pain and suffering. Unlike the staff in Lawton's study, for the staff in the current study suffering was far broader than physical pain. This aligns with the notion of total pain proposed by Cicely Saunders - the founder of the modern hospice and palliative care movement - which sought to humanize the dying process by acknowledging that suffering is far broader than physical matters of sensation (Clark, 1999: 734). Thus, suffering is seen as physical and

emotional, biological and cultural, spiritual and existential, as it pervades every aspect of terminally ill patients' lives (Bendelow and Williams, 1995: 160). Although the management of pain and symptom control were a central issue for the staff, and in contrast to what happened in Lawton's (2000) study, they did not believe that the suffering experienced by terminally ill patients could solely be reduced or eliminated through these methods. The story recounted by a nurse about an 80-year-old woman with non-Hodgkin's lymphoma who suffered from mutism (i.e. a psychiatric disorder in which a patient who is normally capable of speech is unable to speak) at the time of admission into the palliative care unit illustrated how the psychological support offered by the palliative care staff might reduce patients' suffering and improve their well-being:

We have a lady here that when she was admitted into the unit was very prostrated. She was almost in a coma. From time to time she opened her eyes. Now she is using a wheelchair. She was bed-bound for so long that we couldn't make her walk. But she now eats in the living room. She interacts with the patients. She eats by herself. She speaks with us. We were told at the time of her admission that the symptoms she was experiencing were not controlled. That she was dehydrated. But this did not explain why she suffered from mutism. This was voluntary. She was giving up. When she came to the unit we thought that she was going to die soon and at this moment this is not so. She gets up every day, she says what she wants to eat, she interacts, she has a good time. This was very much related to the psychological support we offered to her. We realised that her condition was due to her psychological state. I am not saying that she might not have been depressed but that several things could have been avoided if she had had the proper support previously. She is now not the same person as she was at the time of her admission.

(Carla, nurse)

In addition, the story recounted by a spiritual and religious counsellor shows how the social support offered to patients by the palliative care staff might help to reduce their suffering:

I remember that we once had a lady here whose daughter had a cognitive deficit. The lady also had a problem. She was extremely aggressive. However after we talked with her, one day she told us, in her simplicity: I never thought that you would treat me so well, that you would speak to me. We had just talked to the lady as kindly as we talk to other people. 'Please sit here with us.' We used language that she could understand. That kind of thing. And the fact that we sat with the patient and listened to her, heard her crying, and did not try to answer questions that often don't have answers, and cried with her too, this helped her.

(Capri, spiritual and religious counsellor)

Thus, I argue that physical pain was not the only aspect of suffering that palliative care could successfully alleviate, in contrast to Lawton's claims (2000). Nevertheless, there is a need to recognize that suffering is a personal experience (Wilkinson, 2005) and as a result it may sometimes be difficult for palliative care staff to enter into this realm. Having outlined this, it is to a more detailed consideration about the idea that it is possible to 'die with dignity' in palliative care context that I will now turn.

6.5. Perceptions and experiences of dignity at end of life

Research on how patients experience the process of bodily disintegration and decay prior to impending potential death (Lawton, 2000) and its impact on their sense of dignity (Street and Kissane, 2001b) has been scarce. Dignity is a complex concept (Tadd, 2006) and lacks clarity when discussed in relation to dying and its bodily realities (Sandman, 2002). Without further clarification the promotion of the dignity of dying people may be compromised (Tadd, 2006) despite the claims that it is an overarching value or goal which shapes the delivery of services to these people and their families (Chochinov, 2006). The aim of the present section is to remedy this gap. I intend to offer insights into what constitutes dignity for those who are very ill and at the end of life, as well as for those who accompany and care for them in the weeks and days prior death.

As palliative care aims to provide person-centred holistic care to dying patients (McNamara 2004), it was not surprising that all the members of staff (twenty) highlighted a conception of dignity that calls attention to the respect for a patient's uniqueness as a person (Chochinov, 2006). The staff made comments akin to those of a doctor:

I think dignity is related to respect for the person as a whole. As a whole I mean as a total person. As a person in society. As a person with a biography. The person brings with him a biography. Brings a life history that will end. Until a certain point it will not end because it will be a continuation in his children and grandchildren. I think we need to respect the person. Evaluate his needs. Evaluate his interests. And we need to respect it. I think it is the best way to give dignity to that person.

(Carmen, doctor)

An approach to the care of terminally ill patients that ‘extends beyond the attenuation of physical symptoms, encompassing psychological, existential and spiritual aspects of each person’s unique illness experience’ (Chochinov, 2006: 97) became evident in staff accounts. A head-nurse put this strongly by arguing that dignity was not solely related to the respect of each individual as a person, but by saying that palliative care could enhance one’s sense of dignity:

Dignity is to maintain the right of that patient to continue to be a person. Dignity is to look at our patients and continue to care for them as persons. It is to help him in all the dimensions of care. In the sense that he does not have pain. He does not have uncontrolled symptoms. To promote a familial environment. That we could help him to solve some life problems. That we could help him psychologically. For me in a very short phrase dignity means: to look at the patient and always continue to look at him as a person until the end.

(Ciara, head-nurse)

Achieving holistic person-centred care involves the need to recognize that personhood persists in the face of dying and its bodily realities. This ‘incites a compassion disposition’ (Kontos and Naglie, 2007: 567). The idea of compassion can be found in palliative care literature and has been described as ‘a deep awareness of the suffering of another, coupled with the wish to relieve it’ (Chochinov, 2007: 180). The commitment to relieve the suffering of terminally ill patients appears to be at the heart of palliative

care practice and is very much embedded within a broad notion of the person. This latter became apparent in staff accounts of the meaning and experience of dignity at end of life. This comment, for instance, made by a religious and spiritual counselor illustrates this point well:

Someone is worthy of respect not because of what they have done but because they are a person. As long as the person is alive. And not only in these circumstances. Even when the person dies they still deserve a decent treatment for their body (...) Regardless of what the person has done. I do not make any judgments. It is not a question of merit. It has nothing to do with merit. Someone has dignity because they are a person.

(Capri, spiritual and religious counselor)

This is consistent with Kitwood's (1997: 8) notion of personhood as a 'standing or a status that is bestowed upon human beings, by others, in the context of relationship and social being'. Kitwood further argued that 'each person has an absolute value' and as a result we 'have an obligation to treat each other with deep respect' (ibid). Kitwood recognized that 'being-in-itself is sacred' (ibid). In this way, personhood is seen as 'essentially social' and is 'provided or guaranteed by the presence of others' (Kitwood and Bredin, 1992: 275).

The idea that dignity is very much related to respect for the patient as a person (Chochinov et al., 2002) was also made apparent in the accounts provided by almost half of family members (seven out of twenty), who stated that this ideal was very present in the care provided to their loved ones by the palliative care staff. Their

comments were similar to those of the husband of a 62-year-old woman with a malignant glioma:

Dignity is to take care of her, to take care of other patients, as people, albeit they are ill. Dignity is something that we feel. It is felt in the sense that other people take care of her, are concerned with her well-being, provide her support. They make her feel like a person. They treat her with respect.

(Andie, husband)

This view was shared by two male patients. For example, a 59-year-old man with cancer of the liver put it this way:

Dignity is related to the respect that we have for the other person. This is the most important.

(Bob, terminally ill patient)

The concept of ‘basic dignity’ (Norfenfelt, 2004) appears to be relevant here to describe the accounts provided by most of the respondents in this study, in the sense that it refers to a kind of dignity that all individuals have by virtue of being human and thus highlights the idea that individuals cannot be treated with more or less respect because of basic human rights (Nordenfelt, 2009; Jacobson, 2007). This ideal was present in all the accounts mentioned above and appeared to be very much related with the Christian religious values prominent in Portuguese society as it calls attention to the sacred value of human life (Broom, 2012). Despite the processes of secularization that have been

taking place in Portugal, The Roman Catholic Church still has an important role and continues to inform and underpin many of the values upon which this society is based (Vilaça, 2012).

Although the ideal of ‘basic dignity’ was very much present in the accounts given by patients and family members I found another thread within their responses which calls for a kind of dignity that individuals have as integrated and autonomous persons or what could be referred to as ‘personal dignity’ (Nordenfelt, 2004). The accounts provided by three patients (a male and two female patients) suggested that dignity for them was related to the ability to maintain bodily autonomy and thus its loss was understood as an undignified experience (Enes, 2003). A 78-year-old woman with ovarian cancer stated that her loss of ability to act as an autonomous agent had made her feel that she had lost her dignity:

Becky: I think I have lost my dignity.

I: Why do you say this?

Becky: Because I cannot do anything. I cannot dress myself. I cannot buy my clothes. This was a thing that I loved to do. I loved to see the shops. To go to the sales. I did not buy but I liked to see it. This does not exist anymore. I think I don’t have a real life anymore.

(Becky, terminally ill patient)

Also, a few (three) family members stressed the relationship between dignity and bodily autonomy. The wife of a 58-year-old man with cancer of the colon put it in the following way:

I: What does the word dignity mean to you?

Addison: For me it is difficult to say. I don't think there is dignity. I think in the situation that he is in there is no dignity.

I: Why do you think this?

Addison: Because I turn the mirror to myself and I think if I were in his situation it would be very painful. It would be difficult. It would be harder for me than for him. A person who is not independent in any way, a person who has to call someone for their basic needs. I wonder if that's dignity.

(Addison, wife)

The notion of personhood which calls into question an individual's autonomy and accountability of his/her own actions (La Fontaine, 1985) appears to be relevant here. The loss of bodily autonomy experienced by terminally ill patients contradicts the ideal of the pursuit of individual freedom, which has been seen as the hallmark of personhood in modern western society (Hockey and James, 1993: 107). Lawton noted that 'as patients approached death, it thus became increasingly difficult for them to perform those tasks, and enter into those social interactions, that allowed them to be considered persons' (2000: 112). Lawton observed that 'there came a stage in most patients' deterioration at which their visitors' behavior and attitude towards them indicated that, in their perception the person had already gone.' (ibid: 112). This view was shared by a daughter of a 96-year-old woman, who has been in a vegetative state after a stroke episode. For Amelia the loss of bodily autonomy and independence in terms of cognitive acuity experienced by her mother inevitably led to a loss of personhood. As she put it:

A person who is... let's admit it... a vegetable. That can't think. That has no autonomy. That has no pleasure in being alive. She's a thing. She's no longer a person. A person thinks. When a person loses the ability to think, life [from her point of view] no longer has meaning.
(Amelia, daughter)

This account suggested that because her mother had lost the ability to act as the agent of her embodied actions and intentions (Lawton, 2000) she transgressed classificatory schemas (Navon and Morag, 2004) of what it means to be a person (Murphy et al., 1998) and ended up being in a liminal state (Litle et al., 1998). That is, her mother was in a 'kind of limbo' (van Gennep, 1960) or what Turner (1969) would refer to as a 'betwixt and between position' as she was neither 'truly dead' nor 'fully alive' (Mwaria, 1990). What was also interesting in the discourse of this daughter was that she openly acknowledged the suffering that she and her family were experiencing, as the following excerpt from the interview with her shows:

I think it is inglorious! It is painful to see a person like this! It is painful because it is worthless. If we were suffering and fighting for a cause that makes sense. But we are fighting for nothing. It is very painful for the family. And for her it does not bring any benefit. If there is something in her head I don't believe that there is anything good. (...) I don't think this makes any sense for us as a family. Maybe other people would prefer her to be there because she is alive but not me. Honestly I would prefer that she dies. I don't think I am being selfish. It is only my opinion. And it was her opinion too. If she said: I always want to be alive. But it was quite the opposite.
(Amelia, daughter)

Like the relatives of people with severe brain injuries in a study by Kitzinger and Kitzinger (2013), this daughter believed that her mother would prefer to die rather than continuing to live in her current condition. Amelia and her family felt emotionally overwhelmed and this made her wish for her mother to die soon. This account helps to convey the way in which the emotional character of dying and the bodily realities it entails impact on how patients and their families approached and responded to the decay and disintegration of the body alongside the dying process. The wish for a loved one's death could in this light be interpreted as being related to the witnessing of the process of bodily deterioration and decay and not with the conception that once one loses his/her bodily capacity she/he no longer could be considered a person. This is in accord with previous reported research in the hospice context (Payne et al., 1996a) that has suggested that the witnessing of dying and its bodily realities is a very distressing experience. Those involved in the dying process thus should be seen as meaning-making individuals, who are embedded in webs of conscious knowledge and emotional responses (Mamo, 1999).

With the exception of Amelia, who had acknowledged her emotional pain, none of the family members interviewed for the current study had stated that they believed that her loved one was no longer a person. Unlike the family members in Lawton's (2000) study, family members did not use phrases such as 'not the same person', 'not herself', 'too far gone' and 'already left' to talk about a terminally ill patient. Findings here, then, suggested a more nuanced perspective of personhood at the end of life than those presented by Lawton (*ibid*) in her ethnographic study with British hospice patients. I did not find - unlike Lawton - a seemingly exclusive relation between personhood and the

body and bodily capacity. Whilst for a few respondents the loss of bodily autonomy led to a loss of dignity and consequently a loss of personhood, for the majority of them this was not so as they understood personhood as ‘essentially social’ (Kitwood and Bredin, 1992) and thereby dignity as an ‘inherent value of every human being’ (Nordenfelt, 2004).

6.6. Conclusion

This chapter aims to contribute to a better understanding of the indignities experienced by patients at the end of life and the ways in which palliative care is able to maintain or restore patients’ sense of dignity in the face of dying and its bodily realities. The findings outlined here suggest that in the weeks and days prior to their deaths some patients were likely to experience a loss of consciousness which was in certain cases induced by palliative sedation. This was understood by the staff as a practice used to relieve patient’s suffering - namely their existential suffering - when no other options were available (Faisinger et al., 2000; Gonçalves et al., 2003, 2012; Rietjens et al., 2007). The suffering experienced by patients was very much related with their life-circumstances and thus this contradicts Lawton’s (2000) thesis that suffering at the end of life is deeply interwoven with one’s bodily realities. Palliative sedation was a practice openly criticized by Lawton (ibid), who argued that this inevitably leads patients to experience a form of social death. However such an argument is not in accord with my findings, as although some patients had lost their ability to interact with

others - due to a certain extent to palliative sedation - they continued to be treated by family members as well as by palliative care staff as people. The practice of palliative sedation was used by staff for the benefit of patients as it enabled them to die during a deep sleep and thereby it helped to achieve the good death ideal advocated by the proponents of the modern hospice and palliative care movement (Seymour, 1994; 2007).

A good death was described here by staff as one in which the patient died free of pain, without distress, peacefully, quietly and with family support. Although a few members of staff outlined the ideal of personal choice for the achievement of a good death (McNamara, 2004), I found that this situation was rather complex as most of my patients were not openly informed about their impending potential death. The possibility of causing harm to patients (Gonçalves and Castro, 2001) and the belief that the communication of a terminal illness is the responsibility of the family (Cardoso, 2009) help to explain why health care professionals were less likely to discuss a terminal prognosis with the patient than with the family. The family, on the other hand, could put considerable pressure on health care professionals not to disclose the prognosis to the patient (Long, 2004; Gordon and Paci, 1997) as they may believe that if their loved ones lose hope they will lose their will to live and experience a form of social death (Long and Long, 1982; Gordon and Paci, 1997). The familistic nature of Portuguese society is illustrated through the disclosure practices around dying in the sense that it shows the extent to which the care of the self is given to the family (Seale, 1998). I thus concluded that the revivalist discourse which calls for an open awareness of dying (ibid; Walter, 1994) is not a cultural preference in Portugal as it is not in

accord with its familistic nature. The practices of silence around the potential imminence of death indeed need to be located within a 'social embeddedness narrative' (Gordon and Paci, 1997).

It has been argued that in order to die well patients should have their physical, psychological, social and spiritual suffering reduced (McNamara et al., 1994). I nevertheless found that physical suffering was one of the most important aspects that patients and their families wished to be addressed. I noted that the management of pain and the control of symptoms was a central preoccupation for patients as well as for their family so that it often precipitated palliative care admission. Palliative care offered to patients - and their family - the possibility of retaining a degree of control over their decaying and deteriorating bodies (Broom and Cavenagh, 2011). Although the staff gave prominence to the medical responses to pain and to uncontrolled symptoms - as they believed that without an effective management of pain and symptom control it would not be possible to address the other dimensions of care and thus to reduce patients' suffering - they tried to address as well the psychological, social and spiritual dimensions as they strongly believed in an interaction between them. Findings here, then, do not concur with those of Lawton (2000) in the sense that they challenge the argument that palliative care professionals proposed a close relationship between physical pain and suffering.

Attention was also paid to the ways in which patients' decaying and deteriorating bodies impacted upon their sense of dignity. I found that for most of the staff and family members as well as for a few patients in this study dignity was very much related to the respect of a patient's uniqueness as a person (Chochinov et al., 2002; 2006). This

appears to be linked with the notion of basic dignity, which refers to the value that individuals have by virtue of being human (Nordenfelt, 2004, 2009) and has been recognized as a core value of the philosophy and practice of palliative care (Chochinov, 2006). Kitwood's (1997: 8) argument that 'being-in-itself is sacred' was explicitly recognized in the discourse of this group of respondents. In this way, personhood was not understood as a property of individuals (Kitwood and Bredin, 1992). In contrast, the ideal of 'personal dignity', which describes that kind of dignity that individuals have as integrated and autonomous persons (Nordenfelt, 2004; 2006) was highlighted by a few patients and family members. As for these respondents personhood was deeply interwoven with individual's autonomy (La Fontaine, 1985), they viewed the inability to maintain one's bodily autonomy as an undignified experience (Enes, 2003). These responses were found to be profoundly marked by the emotional experience of seeing a body in decline (Mamo, 1999).

Within these accounts I did not find - unlike Lawton (2000) - a seemingly exclusive relation between personhood and the body and bodily capacity but a more nuanced perspective on personhood at end of life. My work provides an alternative to that of Lawton (*ibid*), who argued that the loss of bodily autonomy experienced by terminally ill patients inevitably leads to a loss of personhood. Lawton, from my point of view, overstated the centrality of the body and bodily capacity for the meaning of personhood at end of life and did not take into account the emotional responses that come into play in the face of dying and its bodily realities. I suggest that a broader view of personhood at end of life is needed.

In answering the question posed at the beginning of this chapter - *in the light on the bodily realities of dying is a dignified death something that Portuguese terminally ill patients can realistically hope for?* - I argue that this is something that the patients in this country could expect. This is situated in an understanding that personhood is ‘essentially social’ and thus is ‘provided or guaranteed by the presence of others’ (Kitwood and Bredin, 1992: 275). Within this light, a loss of dignity only occurs when a person is not treated with respect by others and not when someone loses his/her bodily autonomy. This appears to be very much related with the familistic nature of Portuguese society (Andreotti et al, 2001; Dykstra and Fokkema, 2010; Jurado-Guerrero and Naldini, 1996; Lopes, 2006; Reher, 1998; Tavora, 2012) which places greater value on relationships than on individual autonomy. Having outlined its importance, a more detailed consideration of the role of relationships at end of life will be presented in the next chapter.

Chapter Seven

The processes of interaction at end of life: An exploration on dying as relational

7.1. Introduction

The maintenance of a community of care and concern around the dying person has been found to be central to the achievement of a good death (Seale, 1995: 376) - which, as described in the previous chapter, has been the hallmark of hospice and palliative care (Howarth, 2008). The experience of a social death or a death alone does not appear to be in accord with the principles of hospice and palliative care (Ellis, 2010). Indeed, hospice and palliative care aim to prevent a lonely death and the abandonment of those who are very ill and at the end of life (Seale, 2004). The dying person is, thus, perceived within hospice and palliative care as an integrated whole, a social being, with previously established social relationships that need to be taken into account (Froggat, 1997: 130).

The ideal of family accompaniment during the dying experience has been challenged in recent years by late modern processes of individualization (Beck and Beck-Gernsheim, 2001). ‘The cultural pressures on individuals to create and maintain their biography based on personal choices rather than structural forces/traditions’ (Broom and Kirby, 2013: 510) might disrupt the character and meaning of family at end of life. Indeed studies carried out in England and Australia have found that individualized living contexts undermine family interactions at end of life (ibid) and thereby lead to a social death (Lawton, 2000) or what has also been described as a sense of disintegration of self (Broom and Cavenagh, 2011). This is situated in an understanding that individualized living contexts are not compatible with the significance of family relations and support.

Such understanding however might not be applicable to countries like Portugal (Aboim et al., 2013) - which in contrast to England and Australia - are characterized by a strong familistic nature (Glaser and Tomassini, 2000). Thus, I suggest that a more nuanced perspective is needed in order to understand interpersonal interactions at end of life.

In light of the discussion above, I raise the question: *are terminally ill patients in Portugal likely to experience a social death prior to their physical cessation?* As a way of answering to this question and as families are clearly implicated in the discourse of the lonely death and its avoidance attention will be paid within this chapter to the role of families at end of life. In the first part I examine how families shape and constrain palliative care admission. Family dynamics at the end of life are analyzed in the second section. Attention is given to family practices at the end of life, namely to food and feeding practices, in the third section of this chapter. As the support given by palliative care professionals might prevent a lonely death and feelings of abandonment I look at the last section to the interaction between patients and these professionals.

7.2. Palliative care admission: The role of families

The importance of family at end of life has been emphasised within palliative care where it tends to be understood as the unit of care (Froggat, 1997; Howarth, 2008). The family has been found to mediate the process of dying (Grande et al., 2011; Hudson et al., 2004; Hudson and Payne, 2011; Kramer et al., 2006), namely to influence the place of death (Broom and Kirby, 2013; Thomas et al., 2004). While it has been shown in

Chapter Six as well as elsewhere (Lawton, 2000; Ellis, 2010) that the management of pain and symptom control is one of the major reasons for patients being admitted into hospice/palliative care, other factors may also come into play such as the inability of families to cope with the dying process and its bodily realities (Broom and Kirby, 2013; Broom and Cavenagh, 2011). The aim of this section is to provide a better understanding of the role of the family at end of life, namely how they shape and constrain patients' entry into palliative care.

As detailed in Chapter Five, admission into the palliative care unit was understood by most terminally ill patients as a necessity to alleviate the burden placed by them on their loved ones. In line with this, I concluded that the admission into the palliative care unit was more often than not a product of families. Indeed the accounts provided by a few family members (four) indicated that it was their incapacity to cope with their loved one's illness, as they felt physically and emotionally exhausted, that precipitated admission into the palliative care unit. Their comments were akin to those of a daughter of a 66-year-old woman with tongue cancer, who stated that she was so exhausted of caring for her mother that she had had to take medication for severe anxiety:

I asked the doctor [for her mother to be admitted into the palliative care unit]. I told her: 'I cannot work with my mother in these conditions. I've had to quit my work'. I was also exhausted. I didn't feel better even with the medication. I take Cipralext. I take Xanax. [both for severe anxiety and panic attacks] My hands were shaking, my heart sped, I was dizzy. I said: oh my God this is not life! Then with the children: one has seven the other thirteen. School, swimming, football. A lot of things.

(Amanda, daughter)

In accordance with Clark et al. (2006), Kramer et al. (2006) and Harding and Higginson (2003), I found that the families of those who are very ill and at the end of life face huge responsibilities which end up damaging their well-being. The accounts provided by some members of staff (seven) reinforced the view that the physical and emotional exhaustion of some families was a central reason for patients' admission into the palliative care unit. Their comments were similar to those of a volunteer, who stated that family members may experience certain difficulties in caring for their dying relative which inevitably lead to what has been called in the psychological literature a burn-out:

There are patients who come here due to the burn-out of their family. The burn-out of their caregiver. Very often the patient is cared for by a daughter-in-law, by a daughter or by a son. That is, by a close relative. They may experience difficulties in relation to several things. For instance, changing the patient's diaper. Changing his position in bed. Because a body is heavy. Even if the patient is slim. There is also the emotional burn-out. Because they are seeing 24 hours per day the person they love dying and this is emotionally very tiring. They reach a point of burn-out. Several times the patient is admitted to the unit because the relatives are very tired and cannot help him anymore.

(Chandler, volunteer)

In addition to reducing carer burden, the appeal of palliative care lies in its potential to manage the dying process and its bodily realities. Half of the family members (10 out of 20) indicated that they could not care for their loved one at home as they were not able to provide the care that she/he needed and this precipitated admission into the palliative care unit. Their comments were akin to those of the daughter of an 87-year-old man with bladder cancer:

What precipitated palliative care admission was the fact that my father lived alone and needed physical help. At the time he was admitted he was very weak. He was not able to get up. He was not able to stand on his feet. He would fall down. He was not able to eat alone. He was not able to be alone at home.

(Adele, daughter)

The daughter of a 96-year-old woman, who was in a vegetative state, put this even more strongly by explicitly stating that she did not have adequate conditions at home to care for her dying mother as in order to do so she would have had to transform her home into a hospital unit:

It was not possible. I was not able to have her in these conditions at home. I had to transform my house and the room into a hospital unit. She would not be so well cared for as she is here now. It was not possible to have her at home.

(Amelia, daughter)

There is indeed the belief that the home environment is not able to adequately accommodate the needs of those who are very ill and at the end of life. This is in accord with previous reported research on older and ill people's preferences for place of care at the end of life (Gott et al., 2004; Seymour et al., 2007; Thomas et al., 2004), where concerns have been raised about the quality of care that can be delivered at home in terms of providing adequate symptom and pain relief as well of accommodating health

technologies. These latter could compromise the very essence of home as it has been found elsewhere that the experiences and practices within the home are disrupted and reconfigured from logics transposed from the health care field (Angus et al., 2004). When medical or adaptive equipment enters the home, the materiality of home space and its relationship to biographical meanings and valued social identities are disturbed (Dyck et al., 2005: 175).

What became evident was that palliative care was a valuable alternative when terminally ill patients were not able to be cared for in their own homes (Cannaerts et al., 2004) as it offered families the opportunity to spend the last moments with their loved ones in a supportive and caring environment without having significant concerns related to the dying process and its bodily realities. I suggest that palliative care could promote a space for intimacy (Broom and Cavenagh, 2010) and connection (Broom and Kirby, 2013) and thereby - unlike Lawton (2000) - I argue that the admission into palliative care does not necessarily mean that families will withdraw from contact with their loved ones. A detailed consideration of this issue will be presented in the following section.

7.3. Family relations at the time of dying

The argument that the appeal of hospice/palliative care lies in its potential to hide and control the bodily manifestations of the dying process (Lawton, 2000) provides from my point of view a rather simplistic explanation of its actual role in the sense that it does not take into account - as described in the previous section - that it represents an

important mechanism in which terminally ill patients and their families can be supported through the rise of extra-ordinary demands (Broom and Kirby, 2013). ‘The presumptions that people are making easy, selfish choices and abandoning the hard work of commitment and care’ (Smart and Shipman, 2004: 493) prominent in the individualization thesis (Beck and Beck-Gernsheim, 2001) have indeed been challenged. A number of authors have argued that there is still a deep commitment to what have been called traditional values, like the investment in close personal relationships (e.g. Gross, 2005; Jamieson, 1999; Mason, 2004; Smart, 2007; Smart and Shipman, 2004). Thus, in this section I aim to understand if in a country such as Portugal - which is characterized by a strong familistic nature - processes of individualization might affect family ties at end of life.

To begin with, the accounts provided by half of the family members (10 out of 20) explicitly indicated that they were very much present in the lives of their loved ones. Indeed seven family members stressed that they visit their loved one on a daily basis while three stated that they visit their loved one several times per week. For instance, the daughter of a 71-year-old woman with spongiform encephalopathy, who was in a vegetative state and thus unable to interact with others, stressed that it was very important for her to be with her mother every day as this provided her with some kind of comfort:

I am here every day. This is important to me. My brother and my husband come every Sunday. We do not have holidays. It was what I had to do to feel okay about myself. I enjoy being here. I cannot conceive this in another way.

(Anna, daughter)

The husband of an 80-year-old woman with non-Hodgkin's lymphoma, who had previously suffered from mutism, stated that he felt it was important for his wife to have company:

I come twice per day. I come in the morning. Normally I bring my sister-in-law. That is, my wife's sister, to be with her. I come in the afternoon. Today I came with her. I think my son and my grand-son are with her. They have karate today so normally they visit her before their classes. They are here until six o'clock then they leave. The visits are very good for her! I am always very careful with that.

(Alan, husband)

I thus found that most families were highly supportive at the time of dying. This was confirmed by almost all staff members (15 out of 20). Their comments were akin to those of a nurse:

Normally the visit is daily. More than once per day. The members of the nuclear family tend to visit on a daily basis. If they cannot come in the morning they come in the afternoon. The visits here are 24 hours per day. They also have the chance to stay in the unit during the night. We have some people who choose to stay during the night, especially in an advanced phase of the illness.

(Cecilia, nurse)

The accounts provided by these members of staff also suggested that palliative care encouraged the presence of families during the dying process. Their comments were similar to that of a spiritual and religious counselor:

There is a certain concern on the part of family members to be present. This is an aspect that is taken seriously by palliative care. That is, the family is seen as an important part in the process. We in fact encourage their presence.

(Charlie, spiritual and religious counselor)

This appears to be related to the palliative care ideal of being ‘family centred’ (Froggat, 1997; Clark and Seymour, 1999). The family in this light is seen as the unit of care, not only the patient per se (Howarth, 2008; Kramer et al., 2006). This finding contrasts with those of previous studies conducted in England and Australia, where it is said that support for family is not seen as a priority for palliative care staff (Grande et al., 2009; Hudson et al., 2004; Hudson and Payne, 2011). The staff in the current study gave prominence to the role of family and family relationships at end of life. For instance, a nurse illustrated its importance by stating that ultimately it may help the patient to feel connected to life:

Relationships are the most important thing to these people. The body is sick. They have a disease. Nevertheless their relationships are not sick. There is an illness but there are people who still care for us and connect us to life.

(Claire, nurse)

It is likely that the familistic nature of Portuguese culture (Andreotti et al, 2001; Dykstra and Fokkema, 2010; Jurado-Guerrero and Naldini, 1996; Lopes, 2006; Reher, 1998; Tavora, 2012) plays an important role in explaining why close personal relationships were a strong source of support alongside the process of bodily deterioration and decay prior to impending potential death. Cultural factors might explain why studies conducted in England and Australia have found that the support provided by families to terminally ill patients who were admitted into hospice/palliative care waned over time (Broom and Kirby, 2013; Lawton, 2000). However some studies have noted that families in these countries tended to be supportive while patients were at home and thereby in need (Armstrong-Coster, 2004; Ellis, 2010; Thomas et al., 2002; Ussher et al., 2013). The proximity of patients and their families at end of life in England and Australia might be the result of the needs of assistance of the terminally ill (Dalla Zuanna, 2001; Glaser and Tomassini, 2000; Tomassini et al., 2007). The positive and affirming relations between patients and their families found in this study might reflect a cultural preference (ibid).

There is nevertheless another spectrum of family experiences at end of life whose dynamics were not positive and affirming (Broom and Kirby, 2013). The findings of the current study, in line with those of other studies conducted in England and Australia (ibid; Kind and Quill, 2006; Kramer et al., 2006; Winter and Parks, 2008), suggested that the struggles and difficulties that patients and their families have to deal with persisted to the point of dying. This was mentioned by a few (four) members of staff in the interviews I held with them. For instance, a nurse spoke about the ways in which the

accompaniment of patients may vary according to the relationship previously established as follows:

I think it depends on previous relationships. When a person is ill s/he is more or less the same person. She/he is the same person. If he/she previously had struggles and difficulties in his/her relationship with family members it is not because she/he is ill that things will change. Being ill does not make him/her a saint.

(Clara, nurse)

The case of a 59-year-old man with liver cancer who pointed out that he never had contact with his blood relatives helps to illustrate how family tensions and conflicts persist at the time of dying:

I never had a mother or a father. They never wanted to know about me. I was raised by two persons who had already passed away. They were my 'true' mother and grandmother. My father has had four sons, and my mother two, but we never got along well.

(Bob, terminally ill patient)

What was also interesting was that my findings suggested that the support of 'extended' family and friends appeared to diminish as the dying process escalated. This was spoken about by a few (five) members of staff, as the following account provided by a religious and spiritual counselor shows:

People here are not abandoned by their family. There is however a separation from friends. This is so because people have many problems being in a unit like this. They have many problems with being close to death. They think: 'He must be in a state that I will not recognize him. I will not be able to handle it.' So people don't come. They tell the family that they would like to come but they can't. This is terrible for the patient. Because he realizes that death is very close. So I think in relation to friends there is a separation. They don't feel able to deal with this situation. With the family I don't think this is so.
(Capri, spiritual and religious counselor)

The sense of separation from 'extended' family and friends was spoken about by a 52-year-old man with esophageal cancer as follows:

Normally I only have visits from my godfather. When I was at the hospital one friend or another from my neighborhood came. Now this is unusual. I only have visits from my godfather. I realized that I could only count on his help. With anyone else. I could not count on the support of anyone else.

(Ben, terminally ill patient)

Unlike what happened in Broom and Kirby's (2013) and Lawton's (2000) studies, the absence of physical presence was uncommon among 'immediate' family members. The few exceptions where the 'immediate' family was not present at the time of dying were due to the tensions and conflicts that existed prior to the illness and not to the bodily realities of dying per se - as Lawton (ibid) previously indicated in her work with hospice patients. Indeed Lawton (ibid: 164) found that family and friends avoided contact with hospice patients who were often left in a situation of profound social isolation as they felt repelled by the smells and substances emitted from the patient's body. The findings

of the current study suggest a more nuanced picture of relationships at end of life in the sense that it shows that while ‘extended’ family and friends were likely to withdraw their contact with the terminally ill, ‘immediate’ family tended to be present throughout the dying process. I therefore contradict Lawton’s (ibid) argument that terminally ill patients are left alone by their ‘immediate’ family. It seems that despite the processes of individualization that are taking place in Portugal (Aboim et al., 2013) and elsewhere (Beck and Beck-Gernsheim, 2001), there is still a strong investment in close family ties (Smart, 2007; Smart and Shipman, 2004). Attention will be paid now to the maintenance of family practices at end of life.

7.4. Family practices at end of life: The role of food

Food and feeding practices have been found to be central to individual and familial identity (Fischler, 1988; Charles and Kerr, 1988). Research on how the inability to eat and to engage in mealtime routines disrupts and intrudes on the relationship between patients and their family members has however been scarce and the aim of the present section is to overcome this. In both the palliative care units where this study was carried out patients had four meals a day - breakfast (around 9am), lunch (around 12pm), an afternoon snack (around 3pm) and an evening meal (around 7pm). A homemade meal with three courses, namely a soup, a main and a desert, were offered to patients at lunch and dinner time. The patients were asked if they would like to have a restricted (boiled fish or meat with boiled vegetables) or a regular meal. The food was pureed for the

patients who were experiencing difficulties in swallowing. These patients had the chance to taste the food they enjoyed albeit in a liquid form. The portions offered to patients were small/average as most of them were not able to eat a large meal. This avoided the wasting of food and diminished the pressure that patients could feel around their inability to eat due to a lack of appetite. Although patients could ask to be served with more food none of them did. Food was prepared and managed in the kitchen and was offered to patients on trays in a finished form. The patients who were not able to eat by themselves were helped by their family or by nurses or their auxiliaries. This created a sense of intimacy and personalization (Ellis, 2010). Although patients were invited to eat in the dining room most of them preferred to eat in the privacy of their own rooms, namely in bed or in their armchair as they felt too tired to move between spaces.

Echoing Ellis's (2010) work, I found that food and feeding practices provided a focus around which interactions between patients and family members took place. The effort made by families to be present at mealtimes was directly spoken about by some (11) staff members, who understood it as an 'act of nurturance' (Hughes and Neal, 2000). For instance, a physiotherapist stated that the giving of food was seen by family members as a way of expressing their love for the patient and that they felt a sense of reward for being present at mealtimes:

Usually people try to be as proactive as possible in relation to food. Food is always something that family members like to provide. This has to do with our history. It's a way to show affection. That is, that they care in some way. So people like to feed their relatives. At dinner or lunch time the family is often present.

(Chris, physiotherapist)

The statement above also suggests that food and feeding practices were likely to be seen by patients and their families as important acts because of their symbolic nature. This is consistent with previous research on food. The importance of shared family meals as a means of uniting the family and producing a familial identity was made apparent in Lupton's (1994) study of childhood memories of food. The participants in Lupton's (ibid) study interpreted the word 'food' as a family food event, which was very much related to the concept of a proper meal as defined by Murcott (1982, 1983) - a cooked dinner usually prepared by the mother for the husband and children. The shared family meal was understood by Lupton not only as an important site for the (re)construction of the family, but also for the establishment of emotional ties and power relations. The importance of mealtime routines in promoting familial and individual identities has also been shown in Valentine's (1999) study of food consumption and the spatial dynamics of food and eating. Valentine showed how the consumption of particular foods at home located individuals and household members in shared narratives of identity. As Ellis (2010: 152) pointed out, 'food and feeding practices within western families are inextricably intermeshed with the construction and experience of being a collective and part of something greater than one's self – i.e. the family'. This is illustrated by an episode recounted by a 69-year-old woman with esophageal cancer who expressed her sadness at not been able to participate in the Christmas meal:

Bridget: I have not been able to walk for more than a year. Last year at Christmas I sat at the table but with the help of a wheelchair. This year I was not able to go. It was in my home. Normally I went to the house of my daughter. But this year I stayed at home. It was a very sad Christmas.

I: Did you stay in bed?

Bridget: Yes, I stayed in my bed.

I: How did you react to it?

Bridget: Very badly. Very badly. Because I was not able to sit at the table. It was the first time that this had happened.

(Bridget, terminally ill patient)

In line with existing research concerning food and feeding practices at end of life (Ellis, 2010; Hopkins, 2004; Hopkinson and Corner, 2006), the findings of the current study indicated that the inability to eat and thus to participate in mealtimes had a disruptive impact on the lives of terminally ill patients and their families. Like the family members in Poole and Froggat's (2002) and Strasser et al.'s (2007) studies, some (six) family members in this study highlighted the importance of food and feeding practices. Three family members stressed that they liked to feed their relatives, one that she liked to be present at mealtimes despite the fact that her relative did not want to be fed by her, and another two commented that they often brought homemade food for their loved one as they knew he/she would enjoy it. This latter could made relatives feel less helpless in the face of an imminent dramatic life-event (Raijmakers et al., 2013). For instance, the wife of a 69-year-old male with prostate cancer stated that she often cooked some food at home and brought it in as she knew her husband would like and thus would eat it:

Sometimes I bring homemade food. For instance, today I brought a soup. I think he is nauseated. He never liked liquid soup. Now

everything is liquid. Because he has some difficulties in swallowing everything is liquid now. I sometimes see that he is nauseated. Meat he never liked. For instance, today I brought a green bean soup. The green bean was crushed and he ate it very well.

(Anastasia, wife)

The account above indicates that food knowledge has an important relational significance as having knowledge about a patient's food preferences gives a privileged knowledge about his/her identity and thus creates a sense of 'us-ness' and belonging (Ellis, 2010: 160). As Ellis (ibid: 156) pointed out, 'knowing about a relative's eating practices is a source of relational knowledge acquired and embedded within everyday family life which is also symbolic of the familiarity that characterizes being part of a relationship/family'. I observed that more often than not family members brought from home certain food items that they knew patients would like, namely cakes, biscuits, chocolates, yogurts, and fruit juice, which served as what Seale (1998: 164) called 'temptations to life'. Unfortunately, most of these food items were not eaten by patients who as death approached experienced a decline in and eventual cessation of appetite (ibid).

Also, my findings suggest that when it got to the stage where feeding was no longer of benefit to the patient this was often quite problematic. As in Resende's (1999) study about nutritional refusal of Portuguese terminally ill patients, there was the belief amongst family members that through feeding the bonds between them and their loved ones were maintained. The inability to help to feed their loved ones ultimately led some family members to question their role in the patient's life. This was for instance the case

for Albert, aged 67, who was married to Beatrice for almost 30 years. Beatrice, aged 68, had been diagnosed with a tumor occult (i.e. a tumor that was hidden or so small that it could not be found) some months before her admission into the palliative care unit. For Albert, the provision of feeding enabled him to feel connected with his wife. Albert went to the palliative care facility every day at lunch and dinner time to give a meal to his wife. In the interview I held with him, Albert indicated that he understood the giving of food as a way to return the care he had received from his wife during their marriage. In the later stages of her illness, Beatrice became very agitated and confused and was therefore sedated by staff. A number of complications emerged and the staff decided that feeding was no longer of benefit to Beatrice. The following comment made by Cecilia in a team meeting suggests that Albert experienced feelings of frustration because he was no longer able to perform his food-related role and thereby he felt that he had lost his identity as a husband:

In the weekly team meeting, Cecilia [nurse] noted that Beatrice's husband was very disturbed because he was no longer able to feed his wife: 'Yesterday I spoke with Albert about his wife's inability to eat and he told me that he was very concerned about this. He said that he felt useless. I am very concerned about Albert. I think he does not know how to deal with this situation.'

(Extract from field notes)

Findings here, then, suggested that family members frequently felt a moral obligation to reciprocate the nurturance they have received from their loved ones during the years that they have spent together through food-related roles. This concurs with other

empirical studies. For instance, Atta-Konadu et al. (2010) observed that the desire to reciprocate the nurturance that spousal male carers had received from their wives with dementia compelled these men to engage in the shifting of food roles. Sliding into food roles was understood by spousal male care partners in Atta-Konadu et al.'s (ibid) study as a means of honoring their female partner and staying connected with them. In a similar way to Atta-Konadu et al. (ibid), Genoe et al. (2010) noted that giving and receiving food served as a connection between those who suffer from dementia and their family partners in care.

I also found, in line with Hughes and Neal's (2000) study, that decrease in food intake was a major source of anxiety to family members. This was particularly evident in the discourses of a few staff members (three). The following account provided by a nurse illustrates the difficulties that staff members had in explaining to the family why the provision of food was no longer of benefit to the patient. This nurse stressed that family members were often afraid that the decline in food intake could precipitate a patient's death:

The family thinks that if we don't feed their relatives they will die. It seems that we are hastening death. So it's complicated. Nutrition is difficult to talk about with the family. Because we have to explain that feeding will not bring any benefit to the patient.

(Chloe, nurse)

The account above suggests that family members erroneously believed that the increase on food intake would delay patient's impending potential death (Reid et al., 2009). 'The provision of food', as McInerney (1992: 1271) pointed out, 'is primarily an issue of the

symbolic nature of food and feeding'. Indeed its symbolic meaning appears to transcend the physical benefit it provides to terminally ill patients (Scanlon and Fleming, 1989; Miles, 1987). The provision of food could be to a certain extent interpreted as a defense mechanism employed by family members as a means to avoid dealing with and accepting their loved one's terminal condition (Reid et al., 2009). What became evident in my study was that food intake was viewed by some family members as a way to 'fight back' against the illness (McClement et al., 2003) and to slow down patients' imminent death (Reid et al., 2009) as it maintained the functioning of their body (Moss et al., 2007).

Findings here, then, support the argument that food and feeding practices have a particular symbolic significance and that it dramatically affects interpersonal interactions at the end of life (Ellis, 2010; Hopkins, 2004; Hopkinson and Corner, 2006). Not eating, as Seale (1998: 165) pointed out, 'mirrors the decline of the body and eventual extinction of life itself, leading eventually to the withdrawal of the self in a final fall from culture'. Having outlined the fact that terminally ill patients might not be able to conform to certain social norms, I question if they will inevitably be seen by other people, in particular by their family, as different (Lawton, 2000), and thereby end up in a liminal state (van Gennep, 1960; Turner, 1969). I also question if hospice/palliative care and its family ideology might offer a sense of belonging to terminally ill patients rather than promoting a sense of dislocation (Broom and Cavenagh, 2011). A detailed analysis of these issues will be presented in the next section.

7.5. The hospice as a space of intimacy and belonging

Lawton (2000) has provided a powerful critique of hospices by arguing that these ‘no-spaces’ sequester dying and its bodily realities by setting it apart from mainstream society. Although hospices need to be considered within the context of an increasingly sanitized western culture (Broom and Cavenagh, 2010), the situation appears to be rather more complex (ibid, 2011). The hospice may offer to terminally ill patients certain possibilities, namely a space for living their last moments without the concern of being a burden on their loving relatives (Broom and Cavenagh, 2011; Broom and Kirby, 2013). Little is known about how terminally ill patients and their families understand the hospice/palliative care environment and the kinds of interactions it promotes. Thus the present section aims to provide another lens for understanding if palliative care enhances a sense of dislocation (Broom and Cavenagh, 2011) or what has been described as a liminal state/space (Froggat, 1997). I intend to provide an alternative to work that has suggested that the sense of disintegration of self is an inevitable element of the dying experience (Broom and Cavenagh, 2011; Lawton, 2000). Attention will be paid to the atmosphere and the interactions that take place within palliative care.

More than half of family members (11 out of 20) explicitly stated in the interviews I held with them that they felt very satisfied with the care provided to their loved ones by palliative care professionals. As the son of an 85-year-old man with cancer of the rectum puts it:

We have been supported by the psychologist. We also had a conversation with the spiritual and religious counselor. This is very important! Another good thing is the fact that all the clinical team: doctors, nurses and auxiliary nurses are always available. I ask them and they are always ready to help. So I think the care here is great!

(Aaron, son)

The daughter of a 96-year-old woman who was in a vegetative state compared the care provided in the palliative care unit to that provided in hospital and stated that she believed that her mother was still alive because of the good care provided in the palliative care unit:

I think she only lives because she is well cared for. I don't have anything against public hospitals. I think people there make a huge effort but they have other kinds of condition. I think that if she was in a public hospital she may not be alive. Maybe yes. Maybe no. I don't have any doubt that she is well cared for here. She is very well cared for. I think this has prolonged her life.

(Amelia, daughter)

In addition to instrumental care, the emotional and psychological support offered to patients was understood by family members as one of the major benefits of palliative care. Their accounts lend support to James's (1992) theory that emotional labour - which involves dealing in a conscious way with other people's feelings or emotions (James, 1989; Hochschild, 1979) - is a significant component of hospice/palliative care. For instance, the daughter of a 64-year-old woman with breast cancer recognized the

effort made by palliative care staff to manage her mother's emotions and thus to increase her well-being as follows:

I think they are great here! It is very difficult for someone to talk with her and they are doing it. This shows their effort in helping her. They are helping her to be calmer and to cooperate.

(April, daughter)

Similarly to Thomas et al. (2004), I found that palliative care was evaluated by terminally ill patients and their families in positive terms. Indeed almost all of the patients (nine out of 10) felt satisfied about being at the palliative care unit and were happy with the care provided by palliative care professionals. The only exception was a 52-year-old patient with esophageal cancer, who pointed out that at the hospital he felt less isolated and thus he was more satisfied with being there than in the palliative care unit. Most patients nevertheless made comments like those of a 78-year-old woman with ovarian cancer:

I think they are great! I think everything is great here! They are very affectionate and careful! They are affectionate in every way!

(Becky, terminally ill patients)

This respondent, like the patients in Cannaerts et al.'s study (2004), related her positive experience with palliative care and with the affection that the staff demonstrated when caring for her. For other respondents their positive experiences within palliative care

derived from its cheerful and friendly environment, as the following account given by a 68-year-old woman with ovarian cancer shows:

I like to be here. They are great! They are very nice! I get along well with all of them. It's a laugh all day! It's a joy! They all like me. I've never been in a place like this and I never saw a place like this.

(Beatrice, terminally ill patient)

Humorous interactions have indeed been found to play a central role in everyday palliative care work (Adamle and Ludwick, 2005). Through the displaying of humor and fun palliative care staff were able to create a safe and comforting environment for terminally ill patients (ibid: 289). This resonates with Fox's (1999) thesis that humor can 'produce a fleeting moment of light relief in the midst of an arid accountancy' (ibid: 441) or what could also be referred to as a serious situation (Li, 2002: 197). For the patients in the current study, unlike for the patients in Broom and Cavenagh's (2011) study, the palliative care unit was not a kind of liminal space - i.e. a space which 'promotes a sense of dislocation from one's own reality and disrupts a sense of authenticity within interpersonal dynamics' (ibid: 109). The accounts provided by patients suggested that the appeal of palliative care lies in its ability to create a positive atmosphere and this was instigated by the relation established between them and staff. This relationship was understood by most members of staff (17 out of 20) as being utterly positive, and they spoke about it as being a close and trustful one. Their comments were akin to those of a nurse:

It is a close relation. Because we end up being with the patient all the time. 24 hours per day. We are with him during the night. We are with him during the morning. We are with him during the afternoon. We put him to sleep and we wake him up. So I think it is a very close relation. We also end up being their confidantes. We end up listening to intimate aspects of their lives. I mean private aspects. They tell us secrets.

(Carl, nurse)

The members of staff more often than not employed the ideology of family to describe the palliative care atmosphere and the interactions that take place within it, in the sense that it illustrated the extent to which they are able to create an informal environment where patients feel at ease and able to freely express themselves (Hunt, 1991) . As a nurse put it:

There is a gaining of trust, without any doubt. They begin to know us, we begin to know them. There is a gaining of confidence. They end up feeling comfortable with us. Thus it becomes a familial environment.

(Clara, nurse)

The idea that patients and palliative care staff ‘become like family’ was directly spoken about by a spiritual and religious counselor:

They end up understanding palliative care professionals as their family in this particular context of their life. We celebrate their birthdays. We celebrate important moments of their lives.

(Charlie, spiritual and religious counselor)

The metaphor of the family leads to a sense of intimacy and belonging (Froggat, 1997) and thus it enables identification with the provision of good home care (Exley and Allen, 2007). Home is often constructed within home care discourses as a ‘social space where individuals are relaxed and at ease, where privacy can be maintained and where individuals’ needs can be met and choice and autonomy augmented’ as well as ‘constructed as founded on loving relationships’. That is, ‘caring about someone is taken as the basis for caring’ (ibid: 2319). Thus, by drawing upon Exley and Allen’s (ibid: 2325) idea that home is more about the social and emotional relationships therein than about a physical space, I suggest that palliative care offers to terminally ill patients the opportunity to be cared for at ‘home’. That is, within a private and comfortable space with the presence of loved ones as well as with the support of health care professionals.

Similar to Kellehear et al. (2009), I found that patients in collaboration with their families also attempted to create a ‘home like environment’ for themselves. Indeed all patients wore their own clothes, whether they were pyjamas/night dresses or day-to-day clothes. This was instigated by palliative care professionals, who believed that the use of one’s own clothes would create a more relaxed atmosphere. Also, I noted that patients normally used their own bathroom items, namely hairbrushes, toothbrushes, toothpaste, moisturizers, shampoos, conditioners, deodorants, shavers. Some patients brought their own radios or CD players and books. A patient installed cable TV in his bedroom so he could watch all the football matches of his favorite team. Two patients

brought their mobile phones so they could speak with their family members and friends. A patient also brought a sacred object with her, namely an image of Mother Mary. Most patients displayed family photos on their bedside tables and/or dressers. This was the case, for instance, for a 58-year-old patient with prostate cancer who had a picture of him, his wife and two adult children on his bedside table. In the interview I held with Brad he showed me this picture in order to introduce his family and said that it was taken a few weeks ago when he went out for lunch with them. What this suggested is that the display of family photographs not only helped to create a unique environment for patients of a 'home away from home' (Kellehear et al., 2007), but also confirmed the character of a given relationship, namely that of family (Finch, 2007). Finch (2007), in her work on contemporary family relations, argued that 'in a world where families are defined by the qualitative character of relationships rather than by membership, and where individual identities are deeply bound up with those relationships, all relationships require an element of display to sustain them as family relationships' (ibid: 71). Hence, physical objects like photographs or other domestic artefacts can be understood as 'tools' for the display of family life (ibid: 77). The importance that patients tended to afford to their personal items is in sharp contrast to that found by Lawton (2000), who observed that it was extremely unusual for patients to bring personal items with them to the hospice.

Findings here, then, do not lend support to Broom and Cavenagh's (2011) and Lawton's (2000) argument that the interactions established within palliative care enhance a form of dislocation. Thus, I argue that palliative care - at least in Portugal - cannot be

understood as a kind of a liminal space or what Lawton (ibid) would refer to as a 'no-space'.

7.6. Conclusion

Findings presented here contribute to a better understanding of family dynamics at end of life. Family support may prevent situations of profound social isolation during the dying process and not surprisingly families are directly implicated within the discourse of the lonely death and its avoidance (Ellis, 2010) advocated by the proponents of the modern hospice and palliative care movement (Howarth, 2008). The support of family at end of life has nevertheless been challenged by individualizing living contexts which have questioned cultural ideas of responsibility and obligation (Beck and Beck-Gernsheim, 2001; Broom and Kirby, 2013). Thus, there is the need to explore the extent to which families actually support patients at the end of life.

Echoing previous research on ageing and dying, I found that admission into palliative care was usually a product of families (Broom and Cavenagh, 2011; Broom and Kirby, 2013) who were not able to cope with the dying process (Clark et al., 2006; Kramer et al., 2006; Harding and Higginson, 2003) and believed that home was not the proper place to accommodate it (Angus et al., 2004; Gott et al., 2004; Thomas et al., 2004; Seymour et al., 2007). What became apparent in my findings was that the appeal of palliative care lies first and foremost in its ability to reduce the burden on families, as well as on its resources for caring for those who are near death. Thus, I concluded that

palliative care provided a valuable and proper alternative to the home setting (Cannaerts et al., 2004) in the sense that it offered a space in which patients and their family could enjoy each other's company (Broom and Kirby, 2013) without having concerns related with the dying process and its bodily realities (Broom and Cavenagh, 2011).

The findings outlined here suggest that the presence of family was instigated by the philosophy of palliative care which is family-centred and understands the patient as well as the family as the unit of care (Clark and Seymour, 1999; Frogatt, 1997; Howarth, 2008; Kramer et al., 2006). I found that most families were highly supportive and dedicated to their loved ones. This showed that despite the late modern processes of individualisation that are taking place in Portugal (Aboim et al., 2013) and elsewhere (Beck and Beck-Gernsheim, 2001) there is still an investment in strong family bonds (Smart, 2007; Smart and Shipman, 2004). In line with Broom and Kirby (2013), I noted however that there is a broad spectrum of family experiences within the palliative care setting. Although this was the exception, I found situations in which the family was not very supportive at the time of dying. This was very much related with the tensions and conflicts that existed prior to the illness. The absence of physical presence amongst 'immediate' family members was nevertheless uncommon in contrast to what happened in relation to the presence of 'extended' family and friends, whose support waned over time. I thus claim that a more nuanced perspective of family relations at end of life is needed.

The importance of family and its interactionality became particularly evident in relation to practices related to food and feeding (Poole and Froggat, 1997; Strasser et al., 2007). Indeed there was a belief amongst family members that through feeding the bonds

between them and their loved ones would be maintained (Genoe et al., 2010; Resende, 1999). The giving of food was seen by family members as an act of nurturing (Hughes and Neal, 2000). Family members also felt a moral obligation to reciprocate the nurturance they had received from their loved ones (Atta-Konadu et al., 2010). Echoing previous research (Ellis, 2010; Hopkins, 2004; Hopkinson and Corner, 2006), I found that the inability to eat and thus to participate in mealtimes had a disruptive effect on the lives of terminally ill patients as well as of their family members. My findings then are in accord with Ellis's (2010) thesis that food and feeding practices affect processes of relationality at the end of life. I thus questioned if terminally ill patients are likely to feel different from others and to experience what has been termed a liminal state (van Gennep, 1969; Turner, 1969).

What became apparent in my findings was that the interactions that took place within palliative care did not tend to promote a sense of isolation and alienation - unlike in the findings of previous studies (Broom and Cavenagh, 2011; Lawton, 2000). The staff were able to create an environment where patients felt at ease and able to freely express themselves (Hunt, 1991), particularly through humorous episodes (Adamle and Ludwick, 2005). The greater sense of intimacy and belonging of palliative care (Froggat, 1997, Howart, 2008) was present in staff's description of their relationship with the patients and their families. There was indeed an urge to create a home-like environment (Kellehear et al., 2009) The findings outlined here thus did not lend support to the thesis that palliative care is likely to increase patients' sense of dislocation or what has been described as a kind of liminal state (Broom and Cavenagh, 2011; Lawton, 2000). Instead I argue that palliative care offers a place where terminally

ill patients have the opportunity to be cared for 'at home' in the sense that it provides a private and comfortable space where they can enjoy the company of their loved ones while having the medical, social, psychological and spiritual support they need.

To answer the research question posed at the beginning of this chapter - *are terminally ill patients in Portugal likely to experience a social death prior to their physical cessation?* - I argue that patients in this country did not experience a withdrawal from social and reciprocity networks and thereby they did not experience a form of social death. I suggest that the family is clearly implicated in its avoidance in the sense that they offered unconditional support to patients in the face of a tragic event such as one's death. This to a certain extent could be explained by the strong familistic nature of Portuguese society. The spirit of familism draws upon the assumption that 'throughout their life most people seek their own happiness and at the same time that of their nuclear family and - if possible - their relatives' (Zuanna, 2001: 138). Thus, familism 'is not a general attitude toward the traditional family, based on marriage and children, with the bread-winner father and the housewife' (ibid: 139). This mean that 'familism can persist even where traditional family-life declines' (ibid: 139). The social individualization and the increasing pluralisation of families that have been taking place in late modern Portugal have not been found to be incompatible with the significance of family relationships and support (Aboim et al., 2013).

I thus argue that the withdrawal of families observed by Lawton (2000) and Broom and Kirby (2013) has more to do with the individualistic nature of the countries (Tomassini et al., 2007) in which both studies were conducted than with the individualization processes characteristic of late modernity (Beck and Beck-Gernsheim, 2001). In sum,

my findings do not lead support to the thesis that at the time of dying there is a withdrawal from social and reciprocity networks and thereby that terminally ill patients necessarily experience a form of social death prior to their physical cessation (Lawton, 2000).

Chapter Eight

Conclusion

8.1. Introduction

The present chapter aims to provide a discussion of the main findings of this study. The main and subsidiary research questions will be revisited and answered in the first section of this chapter. In the second section the limitations of the study will be analyzed. Recommendations for future research will be presented in the third section. In the fourth section the implications of this study for the practice of palliative care will be discussed. The concluding thoughts will be outlined in the last section. I shall now provide a more detailed consideration about the findings of this study and how they relate to the research questions.

8.2. Key findings

This study intended to explore how and why the sense of self and identity of terminally ill patients in Portugal is affected by the process of bodily deterioration and decay prior to impending potential death. The ethnographic method offered a valuable approach for studying this phenomenon as it provided an in-depth understanding of dying and its bodily realities. Through participant observation and interviewing techniques I was able to capture the experiences of those who are very ill and at the end of life as well as of those who care for them. The employment of a constructionist grounded theory

approach was very helpful in the construction of the conceptual framework of this study. The analyses of the findings were presented in four empirical chapters. The way in which the main and subsidiary research questions of this study relate to the findings will be discussed next and in doing so I will outline the main contributions of the study.

In Chapter Four the first subsidiary question (*To what extent does a visibly altered body affect the sense of self and identity of terminally ill patients? Does it differ by gender?*) was addressed. The findings presented in this chapter outlined the ways in which terminally ill patients experience and deal with a visibly altered body. To date, research that has addressed this issue has been scarce and thereby my aim was first and foremost to address this gap within the sociology of dying. What became apparent in my findings was that physical appearance is a strong matter of concern to patients even in the face of a terminal illness. My findings provide an alternative to those from existing research, which has downplayed the importance of physical appearance at end of life (Lawton, 2000). I provided new and important insights into the interplay of gender and physical appearance at end of life as my findings led me to recognize that due to masculine and feminine norms physical appearance is more a matter of concern to female patients than to their male counterparts. Findings here, then, contradict the thesis that gender differences are not noticeable amongst terminally ill patients (ibid) and thereby offered novel insights into the sociology of health and illness. I offered a more nuanced perspective of how a visibly altered body is interpreted by those who are very ill and at the end of life and thus important contributions were made to the sociology of the body.

A more comprehensive understanding of how a changed physical body is experienced by terminally ill patients was provided in Chapter Five, where the second subsidiary

question of this study (*In what ways does the loss of bodily autonomy affect the sense of self and identity of terminally ill patients? Does it differ by gender?*) was explored. Attention was given here to the loss of ability to act as the agent of one's own embodied actions and intentions and to the lack of corporeal capacity for self-containment experienced by those who are very ill and at the end of life. This loss of bodily autonomy has been described within the literature as largely undifferentiated (Lawton, 2000). What clearly became evident in my findings was that gender is at the heart of this experience. Indeed male and female patients demonstrated different attitudes and expressed dissimilar feelings towards the loss of bodily closure and the loss of ability to act as an autonomous agent. By showing that gender is an important matter when analyzing the experience of loss of bodily autonomy prior to impending potential death I have made valuable contributions to the sociology of health and illness. My findings challenge established theoretical ideas about personhood (ibid) as I did not find evidence that confirms that due to their loss of bodily autonomy terminally ill patients experience a debasement of their personhood. This provides novel and important insights into the sociology of the body.

In Chapter Six the third subsidiary question (*In light of the bodily realities of dying is a dignified death something that Portuguese terminally ill patients can realistically hope for?*) was discussed. Research on how dying and its bodily realities may challenge patients' sense of dignity has been scarce. This study by paying attention to the significance and experience of dignity within the palliative care context from the perspective of terminally ill patients, as well as of those who accompany and care for them, offered new insights into this matter. The thesis that the loss of bodily autonomy

experienced by terminally ill patients inevitably leads to a loss of sense of dignity due to the fact that personhood is deeply interwoven with the body and bodily capacity (Lawton, 2000) is challenged by my findings and thereby the study provides valuable contributions to the sociology of the body. A nuanced perspective on personhood at the end of life which places a great value on relationships became evident in my findings and this offered new insights into the sociology of dying.

Findings related to the fourth subsidiary question (*Are terminally ill patients in Portugal likely to experience a social death prior to their physical cessation?*) presented in Chapter Seven were the key contributions of the study to the sociology of health and illness as they provided an understanding of interpersonal interactions at end of life. My findings contradict existing research (Broom and Cavenagh, 2011) that has suggested that the interactions that take place within palliative care tend to promote a sense of isolation and alienation. Indeed I did not find evidence to support the theory that palliative care increased patients' feelings of disintegration of self (ibid) or what has been described as a kind of liminal state (Lawton, 2000). Findings here led me to conclude that palliative care offers a space where terminally ill patients could enjoy the company of their loved ones without concerns regarding the dying process and its bodily realities. I suggest that palliative care is able to create a home-like environment where patients can die peacefully and with dignity and thereby I offer a counter position to theories that have questioned the role of hospice within the dying process (ibid).

Overall, my findings provide novel and important insights for the sociology of dying as it has been argued elsewhere that hospice/palliative care facilities 'are becoming enclaves in which a particular type of bodily deterioration and decay is set apart from

mainstream society' (Lawton, 2000: 124). What became evident in my findings was a less linear representation of the body during a palliative care death. The theory that claims that the hospice/palliative care 'had become a sequestered space for particularly distressing cases, especially for those involving extreme bodily disintegration and decay' (ibid: 176) is not in accord with my findings as the patients in my study suffered from a number of manifestations of bodily disintegration and decay. Although I recognize that hospice/palliative care 'must be situated within the wider context of an increasingly sanitized western culture' my findings also did not support the thesis that it is a 'no-space' which enables that 'certain ideas about living, personhood and the hygienic, sanitized, somatically bounded body [to] be symbolically enforced and maintained' (ibid: 144).

I was able to interview a selected random sample of terminally ill patients, unlike in previous work (Lawton, 2000) that found that interviews were not viable due to practical problems, namely those related to patients' physical and mental condition. The process of recruiting terminally ill patients willing to take part in the study was not free of challenges. Indeed I found that it was very difficult to recruit terminally ill patients as due to their debilitating and deteriorating condition most of them were not able to be interviewed. What I would like to suggest is that despite such challenges interviews with terminally ill patients are very positive as they give voice to those who are very ill and at the end of life. Through verbal messages I was able to access their point of view and thus to understand their lived world in great depth (Liamputtong, 2007). The study offered important contributions to end of life research more generally by showing that conducting interviews with terminally ill patients is a valuable method of data collection

in palliative care scenarios. Much of the research in this area has been dominated by the accounts of family members and health care professionals (Broom and Kirby, 2013). By making visible the voices of terminally ill patients the study also provided novel insights into existing sociological research in Portugal and elsewhere. This is indeed the first sociological study conducted in Portugal based on accounts of terminally ill patients. End of life research has been an under researched area within Portuguese sociological research (Antunes and Correia, 2009).

Giving insight into how families experience the dying process has been considered a key challenge for end of life research (Addington-Hall, 2007) and this study has made an important contribution to overcoming this. There has been found to be a gap within existing research on how traditional social influences impact on end of life processes (Broom and Kirby, 2013) and by exploring the extent to which families support terminally ill patients my study provided an important contribution to overcoming this. My findings suggest that despite the processes of individualization that are taken place in Portugal (Aboim et al., 2013) there is still an investment in close personal relationships which is shown in the strong presence of immediate family members throughout the dying process. This was very much related with the familistic nature of Portuguese society. Within this society family utility and personal utility are strongly tied and thus support is provided regardless of the person's needs (Tomassini et al., 2007). Therefore the study provides an alternative to accounts which suggest that 'the deterioration of the body and the dissolution of the social web are inseparable, both in interconnected ways, leading to the inexorable disintegration of self' (Lawton, 2000: 185).

In sum, the findings presented in Chapters Four, Five, Six and Seven offer valuable insight into the main question of this study (*Is the sense of self and identity of terminally ill patients in Portugal affected by the process of bodily deterioration and decay prior to impending potential death? If it is affected, how and why?*). What became evident was that despite the detrimental impact the process of bodily deterioration and decay may have on patients' sense of self and identity it did not lead to a debasement of their personhood and thereby my findings challenge the theory that personhood in modern western society is deeply interwoven with the possession of certain bodily capacities and attributes (Lawton, 2000). What I would like to suggest is that when analyzing such processes one needs to look at the specific nature of the society within which the study is taking place. By saying this I mean that the theory that advocates a strong relationship between personhood and the body and bodily capacity can be explained by the individualistic character of the country (e.g. England) within which the study was conducted. The individualization processes characteristic of late modernity (Beck and Beck-Gernsheim, 2001) cannot be the basis to explain such a theory as these processes are not incompatible with the significance of interpersonal relationships (Aboim et al., 2013). What my findings revealed is that the interactions that took place at the end of life are central to the maintenance of one's sense of personhood and that this might be a reflection of the character of a specific culture.

8.3. The limitations of the study

Here I outline the potential limitations of this study. The first is its sample size. I had originally intended to recruit 20 terminally patients. However because most terminally ill patients were not eligible to take part in this study as they were mentally confused, unable to express themselves or too unwell to permit data collection it was only possible to recruit 10 terminally ill patients. A few patients also refused to participate in the study as they did not want to talk about their illness and/or felt too tired to do so. This small sample means that conclusions must be tentative. The sample of patients was predominantly composed of white people and therefore the views and experiences of other ethnic groups were not represented. In the future it will be important to investigate the views and experiences of a more ethnically diverse group of patients.

Although it could have been beneficial to conduct a more longitudinal study where I was able to follow patients throughout the entire dying process of bodily deterioration and decay this was difficult to achieve due to the unpredictability of the disease trajectory as well as time constraints and funding limitations. As the sample of families recruited into the study was not coincidental with the sample of patients recruited due to the practical reasons mentioned I more often than not was not able to interview the members of the same family. As I conducted the interviews at a particular moment in time another limitation was the fact that this just gave a snapshot of the process of bodily deterioration and decay - although I gained a more sustained picture of this process through observations.

Despite the fact that terminally ill patients normally - except when they were mentally confused - had to give their written consent before they were admitted into the palliative

care unit it was surprising that most of them did not have sufficient knowledge about the type of care they would receive in the palliative care setting and did not have an open awareness of their illness. This significantly constrained the interactions established between me and patients as I had to be very careful about the information that I disclosed to them whether in the interviews or alongside the observational period. When patients asked for more information about the illness I had no choice but to tell them that I was not the right person to talk about their illness as I did not have any medical or nursing training and to suggest they pose such questions to a member of staff. I found that it was sometimes very difficult for terminally ill patients to talk about the process of bodily deterioration and decay as it led to emotional turmoil and therefore some of my data drew upon the accounts of family members and palliative care professionals.

Another potential limitation was related to the fact that my observational range was limited to certain events, as observations could only take place after patients and family members had given their written informed consent. As the consent for observational purposes could not be taken for granted in subsequent encounters with patients and family members I constantly had to remind them about my role. The fact that participants knew they were being observed for research purposes could have affected their behavior. This could also be applied to the observation of the interactions between the various members of staff, although my influence during nursing handovers and team meetings was minimal.

As I adopted a grounded theory approach, it would be expected that the theory generated could be employed to study similar problems and settings (Charmaz, 2000: 524). Nevertheless, because my study was conducted specifically in palliative in-patient

care units it is not transferable to other dying settings such as that of a home or a hospital. The study could also not be widely generalized in relation to all palliative care patients. Almost all the patients who took part in the study suffered from cancer and this is one amongst many other types of conditions that patients who die in a palliative care setting suffer from. The study has however provided novel and important insights into how it is to live and to die in a palliative care unit in Portugal from the point of view of advanced stage cancer patients.

8.4. Recommendations for future research

Few studies have explored how and why the sense of self and identity of terminally ill patients is affected by the process of bodily deterioration and decay prior to impending potential death. This study tried to address this gap. However, as the findings reported here refer mostly to cancer patients, I could not explore the experience of patients who suffer from other types of condition. From a sociological point of view, it would be of interest to conduct research that focuses on the process of bodily deterioration and decay experienced by patients suffering from dementia or other neurological diseases. A comparative study between these two groups of patients could provide important insights into the ways in which the process of bodily deterioration and decay might affect individuals in different and complex ways. This could even be extended to patients with a prolonged chronic illness such as heart disease, cerebrovascular disease and chronic respiratory disease.

This study also did not take into account that the ways in which patients live and deal with the process of bodily deterioration and decay may be different in other settings. There is little information available, for instance, on how the process of bodily deterioration and decay is accommodated within the home and thereby further research needs to be developed on this matter. When highlighting the process of bodily deterioration and decay at home, attention should also be paid to the caring role of families by taking into account the enormous economic pressures that they are subject to nowadays in Portugal and elsewhere. A home death could be extremely problematic for families who did not have the financial resources to care for their loved ones at home. For instance, a daughter/son might not be able to leave her/his job to care for her dying father/mother as s/he needs the income that comes from his/her job to pay her/his family bills. I thus suggest that future research should look at the constraints of a home death and the extent to which this might be beneficial for patients as well as for their family.

It has been found elsewhere that people often prefer to be cared for in their own home (Higginson et al., 2013; Gomes et al., 2013b). However there is not significant research on whether individuals' preference for a home death might change over time - namely when confronted with a life-threatening or terminal illness - and how the process of bodily deterioration and decay might influence this (Gomes et al, 2013b). Further research is needed to investigate this issue. A comparative study between Portugal and the UK on the meaning of a home death would be very interesting as it might be shaped by cultural factors. While for Portuguese patients dying at home might be seen as a connection with their living family, for their British counterparts it might be based on

ideas of the autonomous individual (Long, 2004). As dying at home is more than a physical location: it is about the social and emotional relationships that take place within it (Exley and Allen, 2007; Gott et al., 2004; Lowton, 2009), it would be interesting to understand how palliative in-patient care might try to incorporate its meaning into the care provided to patients and their families. This study gave limited consideration to this matter and thus further research needs to be developed.

A comparative study between Portugal and the UK on the experiences of terminally ill patients and their families according to the place of death would be very interesting. Indeed such a study would be able to identify similarities between these two countries - which have a very different nature. Whereas Portugal has a strong familistic nature, the UK is characterized by individualism (Reher, 1998; Andreotti, et al., 2001). This comparative study could be extended to other countries which share with Portugal a familistic nature such as those from the South of Europe like Italy, Greece and Spain. It is worth mentioning that although there has been a substantial increase in the literature on death and dying internationally this area has received little attention in Portugal. The experience of those who are very ill and at the end of life deserves further investigation in this country. There is also little information available within Portuguese sociological literature on how to conduct research with this population. Recommendations for the protection of vulnerable participants as well as of researchers who work on sensitive topics needs to be developed in this country as this omission might compromise the quality of research.

From a methodological point of view, it might be beneficial to conduct repeat sequential interviews throughout the process of bodily deterioration and decay with patients and

their families. It would also be interesting to obtain insights into a shared biography and thereby it might be a good idea in the future to conduct joint interviews with patients and family members. The employment of innovative methodological approaches such as drawing and photographing techniques might be helpful to use in the future to capture the voices of the terminally ill. It is vital to generate more data on the experiences of those who are very ill and at the end of life as this might improve the care offered to them. Much end of life research conducted up until now has focused on the perspectives of families and of health care professionals and not on the perspective of patients per se.

The research reported has paid great attention to the experiences of adults and thus gave limited consideration to the experiences of dying children. There is a need for further research on this matter. My suggestion for future work would be to look at how the process of bodily deterioration and decay experienced by children prior to their impending potential death might affect interpersonal interactions at end of life. The voices of terminally ill children need to be enhanced. By gaining insights into this matter we would be able to improve the quality of the care provided to children with a terminal illness.

8.5. Recommendations for practice

The findings of this study offer some practical implications for the care given to terminally ill patients in the palliative care context. I propose that in order to provide good palliative care to terminally ill patients, it is necessary to understand how the processes of bodily deterioration and decay impact upon terminally ill patients' sense of self and identity. I found that appearance is a matter of concern to patients with a terminal illness as it enables the maintenance of their embodied personhood. Appearance indeed supports a form of biographical continuity from the perspective of patients as well as of those they love. Appearance was also found to be clearly implicated in the reproduction of gendered identities. Thus I suggest that palliative care professionals should consider appearance as an important aspect in the practice of palliative care and of supporting identity and personhood at end of life. The maintenance of familiar items of clothing or the engagement in beauty care practices such as hair styling could help this.

It is also important to have a deep understanding of how changes in terms of patients' functionality affect their identity and personhood. I found that the loss of bodily autonomy and the unreciprocated dependence on others does not lead to a debasement of patients' sense of personhood. This challenges the thesis that personhood in modern western society is deeply interwoven with the body and bodily capacity (Lawton, 2000). The current study highlights the importance of terminally ill patients being seen as a whole person regardless of their bodily attributes and capacities. What became evident in my findings was a notion of personhood that calls into view patient's inherent value as human beings (Kitwood and Bredin, 1992). Drawing upon this notion, I claim that it

is depersonalized social interactions that might lead to a debasement of patient's personhood. Thus, I suggest that it should be recognized that personhood persists in the face of dying and its bodily realities and as a way to recognize this health care professionals should 'see the humanity in a person' (Kontos and Naglie, 2007: 563). There is a need to transcend assumptions about the diminishing of the personhood of patients who lose certain bodily capacities and attributes as this would enable these professionals to act with compassion and to provide holistic person-centred care (ibid).

As a means to providing holistic patient-centred care palliative care professionals should have a deeper understanding of the interpersonal interactions at end of life and my study made an important contribution to this knowledge base. I provided an evidence based account of the nature of relationships at the time of dying. What became evident was that family support might prevent situations of profound social isolation and thereby I argue that palliative care professionals should value their presence and, ultimately, create an environment where they feel valued. For instance, in considering the importance of food and food-related practices for interpersonal interactions I think it would be beneficial if these professionals create strategies to enhance the participation of family members at mealtimes. A strategy could be the offering of a meal to family members as it would enable them to sit and eat with their loved one and would promote a home-like environment. As a way to enhance the relationship between patients and family members I would suggest the creation of a collective memory book where they could place photos and talk about particular moments that marked their relationship. Also, the creation of an 'oral history service' could provide to patients the opportunity to produce a record of their own life story and draw meaning from it (Winslow et al.,

2009). There is evidence that suggests that ‘this process of remembering reinforces their sense of identity at times when circumstances may have changed their identities out of recognition’ (ibid: 128). This record could also serve as a legacy for their family and friends.

The current study shows that dying in a palliative care unit may bring enormous benefits to patients and their families and thereby challenges the theories that suggest that a good death is only possible in one’s own home (e.g. Lawton, 2000). These theories, by arguing that a good death is synonymous with a death at home, are placing an enormous pressure on families who might not be able to care for their loved ones and are at risk of burn-out. When we look at Portuguese reality we note that the support offered by domiciliary palliative care teams in the country is minimal. In 2009, for instance, there were only five teams in the country that offered this type of service and none of them offered support 24 hours per day. There is the need to create around 106 to 160 teams which offer domiciliary support to cover the needs of the Portuguese population (Capelas, 2010). The lack of teams available means that families are often left alone to manage as best they can the dying process and the potential loss of their loved ones. While dealing with the dying process and its bodily realities families might not be able to enjoy the last moments with their loved ones. This appears to me to be extremely problematic.

The accounts of family members indicated that they were not satisfied with the care provided to their loved ones by hospital and domiciliary care teams and the support offered to them. The admission into a palliative care unit was seen as an optimal solution as it enabled them to spend time with their loved ones without having concerns,

regardless of the manifestations associated with the process of bodily deterioration and decay. A recent study suggested that in comparison to other countries (i.e. England, Flanders, Germany, Italy, the Netherlands, Spain) Portugal has the highest percentage of hospice/palliative care preferences for death. A home death preference was found to be higher in other countries than in Portugal. This might be related to the limited availability of services and resources in the community (Gomes et al., 2012). Cultural factors could also help to explain this. The strong familistic nature of Portuguese culture might be at the heart of such preferences. As outlined in this study, terminally ill patients might be afraid to be a burden to their families and thereby might prefer to be cared for by a stranger than by a family member. Traditional values such as obedience to authority (i.e. medical authority) might lead patients to feel safer in institutional settings. It has also been found that survival values (i.e. those that give priority to economic and physical security) are higher in Portugal than in other countries and this might further explain the higher preferences for a hospice/palliative care death (ibid).

Having this in mind I suggest some caution to those authors who argue that the solution to providing good palliative care is related to the creation of more units that provide domiciliary support (Gomes et al., 2013a). This appears to be the best option to care for patients with advanced and terminal illness in the eyes of policy makers and planners as it is a more cost-effective form of care (Lawton, 2000: 123). While a part of the solution might be the creation of domiciliary palliative care teams, there is also from my point of view the urgent need to create more in-patient palliative care units - as there is a considerable lack of this type of service in the country, as demonstrated in Chapter 3. This would enable patients and their families to freely decide the best option for them.

8.6. Final remarks

This study intended to show how and why the sense of self and identity of terminally ill patients in Portugal is affected by the process of bodily deterioration and decay prior to impending potential death. What became evident was that, regardless of the bodily manifestations inherent to the dying process, patients did not suffer a debasement of their personhood. This was mainly due to the interpersonal interactions that took place within the palliative care context. I found that palliative care practice provides a space for interaction where terminally ill patients could spend their last moments with their loved ones without preoccupations around uncontrolled pain and symptoms and at one and the same time this decreased their concerns around being a burden. I noted that the familistic nature of Portuguese culture informs the practice of palliative care in this country in the sense that it sees the patient as well as their family as the unit of care and thereby promotes their inter-personal interaction. The participation of the family is clearly implicated in the avoidance of patient's social death prior to their physical cessation. In light of my findings, I conclude by noting that in the face of dying and its bodily realities, palliative care practice offers to terminally ill patients the opportunity to live fully until their death.

Bibliography

Aalten, A. (2007) Listening to the dancer's body. *The Sociological Review*, 55 (1), pp.109-125.

Aboim, S. (2010). Family and Gender Values in Contemporary Europe: The Attitudinal Gender Gap from a Cross-National Perspective. *Portuguese Journal of Social Science*, 9, (1), pp.33-58.

Aboim, S. Vasconcelos, P. Wall, K. (2013) Support, social networks and the family in Portugal: two decades of research. *International Review of Sociology: Revue Internationale de Sociologie*, 23 (1), pp.47-67.

Adamle, K. Ludwick, R. (2005) Humor in hospice care: who, where and how much? *American Journal of Hospice and Palliative Care*, 22 (4), pp.287-290.

Addington-Hall, J.M. MacDonald, L.D. Anderson, H.R. and Freeling, P. (1991) Dying from cancer: the views of bereaved family and friends about the experiences of terminally ill patients. *Palliative Medicine*, 5, pp.207-214.

Addington-Hall, J. McCarthy, M. (1995) Dying from cancer: results of a national population-based investigation. *Palliative Medicine*, 9, pp.295-305.

Addington-Hall, J. (2002) Research sensitivities to palliative care patients. *European Journal of Cancer Care*, 11, pp.220-224.

Addington-Hall, J. (2007) Introduction. In Addington-Hall, J. Bruera, E. Higginson, I. Payne, S. (eds) *Research Methods in Palliative Care*. Oxford: Oxford University Press.

- Aleksandrova-Yankulovska, S. Have, H. (2013) Survey of Staff and Family Members of Patients in Bulgarian Hospices on the Concept of 'Good Death'. *American Journal of Hospice and Palliative Care*, XX(X) 1-7.
- Allan, G. (1988) Kinship, responsibility and care for elderly people. *Ageing and Society*, 8 (3), pp.249-268.
- Andrews, M. (1999) The seductiveness of agelessness. *Ageing and Society*, 19 (3), pp 301 318.
- Andreotti, A. Garcia, S. Gomez, A. Hespanha, P. Kazepov, Y. Mingione, E. (2001) Does a Southern European Model Exist? *Journal of European Area Studies*, 9 (1), pp. 43-62.
- Angus, J. Kontos, P. Dyck, I. McKeever, P. Poland, B. (2005) The personal significance of home: habitus and the experience of receiving long-term home care. *Sociology of Health and Illness*, 27 (2), pp.161–187.
- Arber S, Vandrevalla T, Daly T, Hampson S. (2008) Understanding gender differences in older people's attitudes towards life-prolonging medical technologies. *Journal of Aging Studies*, 22 (4), pp. 366-375.
- Aries, P. (1981) *The Hour of Our Death*. London: Allen Lane.
- Armstrong, D. (1987) Silence and truth in death and dying. *Social Science and Medicine*, 24 (8), pp.651-657.
- Armstrong-Coster, A. (2004) *Living and dying with cancer*. Cambridge: Cambridge University Press.

Associação Portuguesa de Sociologia (1992) *Código Deontológico*. Lisboa: Associação Portuguesa de Sociologia. Accessed at 1 January 2010: <http://www.aps.pt/?area=000&marea=001&PHPSESSID=bb83c497cb3d696e0680c90388d5fc2c>

Atta-Konadu, E. Keller, H. Daly, K. (2011) The food-related role shift experiences of spousal male care partners and their wives with dementia. *Journal of Aging Studies*, 25 (3), pp.305–315.

Balfe, M. Brugh, R. (2010) Disclosure of STI testing activities by young adults: influence emotions of social networks. *Sociology of Health and Illness*, 32 (7), pp.1041-1058.

Ballard, K. Elston, M.A. Gabe, J. (2005) Beyond the mask: women's experience of public and private ageing during midlife and their use of age-resisting activities. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 9 (2), pp.169-187.

Ballard, K. Elston, M.A. Gabe, J. (2009) Private and public ageing in the UK: the transition through the menopause. *Current Sociology*, 57 (2), pp.269-290.

Batchelor, D. (2001) Hair and cancer chemotherapy: consequences and nursing care – a literature study. *European Journal of Cancer Care*, 10 (3), pp.147-163.

Baumgartner, L.M. (2007) The incorporation of the HIV/AIDS identity into the self over time. *Qualitative Health Research*, 17, pp.919-931.

Beck, U. Beck-Gernsheim, E. (2001) *Individualization: Institutionalized Individualism and its Social and Political Consequences*. London: Sage.

- Beillin, R. (1981) Social functions of denial of death. *Omega: Journal of Death and Dying*, 21, pp.25-35.
- Bendelow, G. (1993) Pain perceptions, gender and emotion. *Sociology of Health and Illness*, 15 (3), pp.273-294.
- Bendelow G. and Williams S.J. (1995) Transcending the dualisms? Towards a sociology of pain. *Sociology of Health and Illness*, 17 (2), pp.139-165.
- Bendelow, G. and Williams, S. (1998) *Emotions in Social Life: Critical Themes and Contemporary Issues*. London: Routledge.
- Bendelow, G. (2006) Pain, suffering and risk. *Health, Risk and Society*, 8 (1), pp.59-70.
- Bennett, K. (2007) ‘No Sissy Stuff’: Towards a theory of masculinity and emotional expression in older widowed men. *Journal of Aging Studies*, 21, pp. 347–356.
- Bernardes, S. Lima, M. (2010) Being less of a man or less of a woman: Perceptions of chronic pain patients’ gender identities. *European Journal of Pain*, 14, pp.194–199.
- Biggs, S. (1997) Choosing not to be old? Masks, bodies and identity management in later life. *Ageing and Society*, 17, pp.555-570.
- Biggs, S. (2004) Age, gender, narratives and masquerades. *Journal of Aging Studies*, 18, 45-58.
- Bolton, S. (2001) Changing faces: nurses as emotional jugglers. *Sociology of Health and Illness*, 23 (1), pp.85-100.
- Boman, J. Jevne, R. (2000) Ethical evaluation in qualitative research. *Qualitative Health Research*, 10 (4), pp.547-554.

- Bordo, S. (1993) *Unbearable Weight: Feminism, Western Culture, and the Body*. London: University of California Press.
- Bourdieu, P. (1984) *Distinction: a Social Critique of the Judgement of Taste*. London: Routledge.
- Bradshaw, A. (1996) The spiritual dimension of hospice: the secularization of an ideal. *Social Science and Medicine*, 43 (3), pp.409-419.
- Bredin, M. (1999) Mastectomy, body image and therapeutic massage: a qualitative study of women's experience. *Journal of Advanced Nursing*, 29 (5), pp.1113-1120.
- Breheny, M. Stephens, C. (2012) Negotiating a moral identity in the context of later life care. *Journal of Aging Studies*, 26, pp.438-447.
- British Sociological Association (2002) *Statement of Ethical Practice for the British Sociological Association*. Durham: The British Sociological Association. Accessed at 1 January 2010: <http://www.britisoc.co.uk/NR/rdonlyres/468F236C-FFD9-4791A0BD4DF73F10BA43/0/>
- Brittain, K. Shaw, C. (2007) The social consequences of living with and dealing with incontinence – a carers perspective. *Social Science and Medicine*, 65, pp.1274-1283.
- Brooker, D. (2007) *Person-centred dementia care*. London: Jessica Kingsley Publishers.
- Broom, A. Cavenagh, J. (2010) Masculinity, moralities and being cared for: An exploration of experiences living and dying in a hospice. *Social Science and Medicine*, 71, pp.869-876.

- Broom, A. Cavenagh, J. (2011) On the meaning and experience of living and dying in Australian hospice. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 15, pp.96-111.
- Broom, A. (2012) On Euthanasia, Resistance, and Redemption: The Moralities and Politics of a Hospice. *Qualitative Health Research*, 22, pp.226-237.
- Broom, A. Kirby, E. (2013) The end of life and the family: hospice patient's view on dying as relational. *Sociology of Health and Illness*, 35 (4), pp. 499–513.
- Brown, C. Jasper, K. (1993) Introduction: Why weight? Why women? Why now? In Brown, C. Jasper, K. (eds) *Consuming Passions: Feminist Approaches to Weight Preoccupation and Eating Disorders*. Second Story: Toronto, pp.16-35.
- Bruera, E. Neumann, C. Mazzocato, C. Stiefel, F. Sala, R. (2000) Attitudes and beliefs of palliative care physicians regarding communication with terminally ill cancer patients. *Palliative Medicine*, 14, pp.287–298.
- Bury M. (1982) Chronic illness as biographical disruption. *Sociology of Health and Illness*, 4 (2), pp.167-182.
- Bury, M. (1988) Meaning at risk: the experience of arthritis. In Anderson, R. and Bury, M. (eds) *Living with Chronic Illness. The Experience of Patients and their Families*. London: Unwin Hyman.
- Bury M. (1991) The sociology of chronic illness: a review. *Sociology of Health and Illness*, 13 (4), pp.451-468.
- Bury, M. (1997) *Health and Illness in a Changing Society*. London: Routledge.

- Bury, M. (2001) Illness narratives: fact or fiction? *Sociology of Health and Illness*, 23 (3), pp.263-285.
- Calnan, M. Badcot , D. Woolhead, G. (2006) Dignity under threat? A study of the experiences of older people in the United Kingdom. *International Journal of Health Services*, 36 (2), pp.355-375.
- Cameron, E., Bernardes, J. (1998). Gender and disadvantage in health: Men's health for a change. *Sociology of Health and Illness*, 20, pp. 673-691.
- Camp, D.L. Finlay, W.M.L. Lyons, E. (2002) Is low self-esteem an inevitable consequence of stigma? An example from women with chronic mental health problems. *Social Science and Medicine*, 55, pp.823-834.
- Cannaerts, N. Casterlé, B. Grypdonck, M. (2004) Palliative Care, Care for Life: A Study of the Specificity of Residential Palliative Care. *Qualitative Health Research*, 14, pp.816-835.
- Canham, S. (2009) The interaction of masculinity and control and its impact on the experience of suffering for an older man. *Journal of Aging Studies*, 23, pp.90-96.
- Cannon, S. (1989) Social research in stressful settings: difficulties for the sociologist studying the treatment of breast cancer. *Sociology of Health and Illness*, 11 (1), pp.62-77.
- Capelas, L. (2009) Cuidados Paliativos: Uma Proposta para Portugal. *Cadernos de Saúde*, 2 (1), pp.51-57.
- Capelas, L. (2010) Equipas de cuidados paliativos domiciliários: quantas e onde são necessárias em Portugal. *Cadernos de Saúde*, 3 (2), pp: 21-26.

- Cardoso, A. (2009) *A comunicação na transição para cuidados paliativos: um estudo exploratório da realidade portuguesa*. Porto: Faculdade de Medicina do Porto.
- Carricaburu, D. Pierett, J. (1995) From biographical disruption to biographical reinforcement.: the case of HIV-positive men. *Sociology of Health and Illness*, 17 (1), pp.65-88.
- Casarett, D. and Karlawish, J. (2000) Are special ethical guidelines needed for palliative care research? *Journal of Pain and Symptom Management*, 20 (2), pp.130-139.
- Cash, T. Brown, T. (1989) Gender and body images: stereotypes and realities. *Sex Roles* 21, (5/6), pp.361-373.
- Cash, T. Price, V. Savin, R. (1993) Psychological effects of androgenetic alopecia on women: comparisons with balding men and with female control subjects. *Journal of the American Academy of Dermatology*, 29 (4), pp.568-575.
- Cassells, C. Watt, E. (2003) The impact of incontinence on older spousal caregivers. *Journal of Advanced Nursing*, 42 (6), pp.607–616.
- Chapman, E. (2000) Conceptualisation of the body for people living with HIV: issues of touch and contamination. *Sociology of Health and Illness*, 22 (6), pp.840-857.
- Chapple, A. and Ziebland, S. (2002) Prostate cancer: embodied experience and perceptions of masculinity. *Sociology of Health and Illness*, 24 (6), pp.820-841.
- Chapple, A. Ziebland, S. McPherson, A. (2004) Stigma, shame and blame experienced by patients with lung cancer: qualitative study. *British Medical Journal*, 328, pp.1470-1475.

Charles, N. Kerr, M. (1988) *Women, Food, and Families*, Manchester: Manchester University Press.

Charmaz K. (1983) Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, 5, pp.168-195.

Charmaz K. (1991) *Good Days, Bad Days: the Self in Chronic Illness and Time*. New Jersey: Rutgers University Press.

Charmaz K. (1994) Identity Dilemmas of Chronically Ill Men. *The Sociological Quarterly*, 35 (2), pp.269-288.

Charmaz K. (1995) The body, identity and self: adapting to impairment, *The Sociological Quarterly*, 36 (4), pp.657-680.

Charmaz, K. and Oleson, V. (1997) Ethnographic research in medical sociology: its foci and distinct contributions. *Sociological Methods Research*, 25 (4), pp.452-494.

Charmaz, K. Mitchell, R. (2001) Grounded theory in ethnography. In Atkinson, P. (eds) *Handbook of Ethnography*. London: Sage.

Charmaz, K. (2006) *Constructing Grounded Theory*. London: Sage.

Chatto, S. Ahmad, W. (2008) The moral economy of selfhood and caring: negotiating boundaries of personal care as embodied moral practice. *Sociology of Health and Illness*, 30 (4), pp. 550–564.

Chau, L. Hegedus, L. Praasman, M. Smith, K. Tsukada, M. Yoshida, K. Renwick, R. (2008) Women living with a spinal cord injury: perceptions about their changed bodies. *Qualitative Health Research*, 18 (2), pp.209-221.

Chochinov, H.M. (2002) Dignity-conserving care: a new model for palliative care. *JAMA*, 287 (17), pp.2253-2260.

Chochinov, H.M. Hack, T. Hassard, T. Kristjanson, L. McClement, S. Harlos, M. (2002a) Dignity in the terminally ill: a cross-sectional, cohort study. *The Lancet*, 360 (21/28), pp.2026-2030.

Chochinov, H.M. Hack, T. McClement, S. Kristjanson, L. Harlos, M. (2002b) Dignity in the terminally ill: a developing empirical model. *Social Science and Medicine*, 54, pp.433-443.

Chochinov, H.M. Kristjanson, L. Hack, T. Hassard, T. McClement, S. Harlos, M. (2007) Burden to others and the terminally ill. *Journal of Pain and Symptom Management*, 34 (5), pp.463-471.

Chochinov, H.M. (2006) Dying, dignity, and new horizons in palliative end of life care. *A Cancer Journal for Clinicians*, 56, pp.84-103.

Chochinov, H.M. (2007) Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. *BMJ: British Medical Journal*, 335, (7612), pp. 184-187.

Christians, C. 2000. Ethics and Politics in Qualitative Research. In Norman K. Denzin and Yvonna S. Lincoln (eds) *Handbook of Qualitative Research*, Thousand Oaks: Sage Publications, Inc.

Clare, L. (2003) Managing threats to self: awareness in early stage Alzheimer's disease. *Social Science and Medicine*, 57, pp.1017-1029.

Clark, D. (1997) What is qualitative research and what can it contribute to palliative care? *Palliative Medicine*, 11, pp.159-166.

Clark, D. (1999) Total pain, disciplinary power and the body in the work of Cicely Saunders, 1958-1967. *Social Science and Medicine*, 49, pp.727-736.

Clark, D. Seymour, J. (1999) *Reflections on Palliative Care*. Buckingham: Open University Press.

Clark, D. (2002) Between hope and acceptance: the medicalization of dying. *British Medical Journal*, pp.324-327.

Clarke, A. Seymour, J. (2010) “At the Foot of a Very Long Ladder”: Discussing the End of Life with Older People and Informal Caregivers. *Journal of Pain and Symptom Management*, 40 (6), pp.857-869.

Clark, D. (2001) What is qualitative research and what can it contribute to palliative care?. In Field, D. et al. (eds) *Researching Palliative Care*. Buckingham: Open University Press.

Clark, D. Ingleton, C. Seymour, J. (2000) Support and supervision in palliative care research. *Palliative Medicine*, 14, pp.441-446.

Clark, M. Rummans, T. Sloan, J. Jensen, A. Atherton, P. Frost, M. Richardson, J. Bostwick, M. Johnson, M. Hanson, J. Brown, P. (2006) Quality of Life of Caregivers of Patients With Advanced-Stage Cancer. *American Journal of Hospice and Palliative Medicine*, 23 (3), pp.185-191.

Classen, C. Howes, D. and Synott, A. (1994) *Aroma: the Cultural History of Smell*. London: Routledge.

Cohen-Mansfield, J. Golander, H. Arnheim, G. (2000) Self-identity in older persons suffering from dementia: preliminary results. *Social Science and Medicine*, 51, pp.381-394.

Connell, R. (1995) *Masculinities*. Oxford: Polity Press.

Courtenay, W. (2000) Constructions of masculinity and their influence on men's well-being: a theory of gender and health. *Social Science and Medicine*, 50, pp.1385-1401.

Costello, J. (2001) Nursing older dying patients: findings from an ethnographic study of death and dying in elderly care wards. *Journal of Advanced Nursing*, 35 (1), pp.59-68.

Crouch, M. McKenzie, H. (2000) Social realities of loss and suffering following mastectomy, *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 4 (2), pp.196-215.

Crouch, M. McKenzie, H. (2006) The logic of small samples in interview-based qualitative research. *Social Science Information*, 45 (4), pp.483-499.

Crossley, N. (1995a) Body Techniques, Agency and Intercorporeality: On Goffman's Relations in Public'. *Sociology*, 29 (1), pp.133-49.

Crossley, N. (1995b) Merleau-Ponty, the Elusive Body and Carnal Sociology. *Body and Society*, 1 (1), pp.43-63.

Crossley, N. (1996) Body-subject/body power: agency, inscription and control in Foucault and Merleau-Ponty. *Body and Society*, 2 (2), pp.99-116.

Crossley, N. (2005) Mapping reflexive body techniques: on body modification and maintenance. *Body and Society*, 11 (1), pp.1-35.

- Crossley, N. (2007) Researching embodiment by way of 'body techniques. *The Sociological Review*, 55 (1), pp.80-94.
- Crossley, M (2007) Evaluating qualitative research. In Addington-Hall, J. (ed) *Research Methods in Palliative Care*. Oxford: Oxford University Press.
- Courtenay, W. (2000) Constructions of masculinity and their influence on men's well-being: a theory of gender and health. *Social Science and Medicine*, 50, pp.1385-1401.
- Crawford, R. (1994) The boundaries of the self and the unhealthy other: reflections on health, culture and AIDS. *Social Science and Medicine*, 38 (10), pp.1347-1365.
- Crawford, R. (2006) Health as a meaningful social practice. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 10 (4), pp.401-420.
- Dalla Zuanna, G. (2001). The banquet of Aeolus: A familistic interpretation of Italy's lowest low fertility. *Demographic Research*, 4 (5), pp. 133-162
- Davis, D. (2004) Dementia: sociological and philosophical constructions. *Social Science and Medicine*, 58, pp.369-378.
- Delamont, S. (2004) Ethnography and participant observation. In Seale, C. et al. (eds) *Qualitative Research Practice*. London: Sage.
- Dickson-Swift, V. James, E. Kippen, S. Liamputtong, P. (2006) Blurring boundaries in qualitative health research on sensitive topics. *Qualitative Health Research*, 16 (6), pp.853-871.

Dickson-Swift, V. James, E. Kippen, S. Liamputtong, P. (2007) Doing sensitive research: what challenges do qualitative researchers face? *Qualitative Research*, 7, pp.327-352.

Dickson-Swift, V. James, E. Liamputtong, P. (2008a) *Undertaking Sensitive Research in the Health and Social Sciences*. Cambridge: Cambridge University Press.

Dickson-Swift, V. James, E. Kippen, S. Liamputtong, P. (2008b) Risk to researchers in qualitative research on sensitive topics: issues and strategies. *Qualitative Health Research*, 18, pp.133-144.

Dickson-Swift, V. James, E. Kippen, S. Liamputtong, P. (2009) Researching sensitive topics: qualitative research as emotion work, *Qualitative Research*, 9, pp.61-79.

Dodson, L. Zinavage, R. (2007) It's like a family: caring labour, exploitation, and race in nursing homes. *Gender and Society*, 21 (6), pp.905-928.

Donorfio, L. Sheehan, N. (2001) Relationship dynamics between aging mothers and caregiving daughters: filial expectations and responsibilities. *Journal of Adult Development*, 8 (1), pp.39-49.

Douglas, M. (1966) *Purity and Danger*. Routledge: New York.

Douglas, M. (1933) *Food in the Social Order*. Routledge: New York.

Duay, D. Bryan, V. (2006) Senior Adults' Perceptions of Successful Aging. *Educational Gerontology*, 32 (6), pp.423-445.

- Ducombe, J. Jessop, J. (2002) Doing rapport and the ethics of faking friendship. In Mauthner, M. Birch, M. Jessop, J. Miller, T (eds) *Ethics in Qualitative Research*. London: Sage.
- Dyck, I. Kontos, P. Angus, J. McKeever, P. (2005) The home as a site for long-term care: meanings and management of bodies and spaces. *Health and Place*, 11, pp.173–185.
- Dykstra, P. Fokkema, T. (2010) Relationships between parents and their adult children: a West European typology of late-life families. *Ageing and Society*, pp.1-25.
- Elias, N. (1985) *The Loneliness of Dying*. Oxford: Basil Blackwell.
- Elias, N. (1994) *The Civilising Process: the History of Manners and State Formation and Civilisation*. Oxford: Blackwell.
- Elliott, J. (2005) *Using Narrative in Social Research*. London: Sage.
- Elliott, J. Olver, I. (2008) Dying cancer patients talk about euthanasia. *Social Science and Medicine*, 67, pp.647-656.
- Ellis, J. (2010) *Family practices during life-threatening illness: exploring the everyday*, unpublished PhD thesis, University of Sheffield.
- Emerson, R. Fretz, R. Shaw, L. (2001) Participant observation and Fieldnotes. In Atkinson, P. (ed) *Handbook of Ethnography*. London: Sage.
- Enes, S. (2003) An exploration of dignity in palliative care. *Palliative Medicine*, 17, pp.263-269.

Entwistle, J. (2000). *The fashioned body: Fashion, dress and modern social theory*. Cambridge, UK: Polity.

Entwistle, V. Tritter, J.Q. Calnan, M. (2002) Researching experiences of cancer: the importance of the methodology. *European Journal of Cancer Care*, 11, pp.232-237.

Exley, C. (2004) Review article: the sociology of dying, death and bereavement. *Sociology of Health and Illness*, 26 (1), pp.110-122.

Exley, C. Letherby, G. (2001) Managing a disrupted lifecourse: issues of identity and emotion work. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 5 (1), pp.112-132.

Exley, C. Allen, D. (2007) A critical examination of home care: End of life care as an illustrative case. *Social Science and Medicine*, 65, pp.2317-2327.

Faircloth, C.A. Boylstein, C. Rittman, M. Young, M.E. Gubrium, J. (2004) Sudden illness and biographical flow in narratives of stroke recovery. *Sociology of Health and Illness*, 26 (2), pp.242-261.

Fainsinger, R. Waller, A. Bercovici, M. Bengtson, K. Landman, W. Hosking, M. Nunez-Olarte, J. deMoissac, D. (2000) A multicentre international study of sedation for uncontrolled symptoms in terminally ill patients. *Palliative Medicine*, 14, pp.257–265.

Featherstone, M. Hepworth, M. (1991) The mask of aging and the postmodern life course. In *Featherstone, M. Hepworth, M. Turner, B. (eds) The Body: Social Process and Cultural Theory*. London: Sage.

- Featherstone, M. (1991) The Body in Consumer Culture. In *Featherstone, M. Hepworth, M. Turner, B. (eds) The Body: Social Process and Cultural Theory*. London: Sage.
- Featherstone, M. (2000) *Body Modification*. London: Sage.
- Field, D. James, N. (1993) Where and how people die. In D. Clark (ed) *The Future for Palliative Care*. Buckingham: Open University Press.
- Field, D. Coop, G. (1999) Communication and awareness about dying in the 1990s. *Palliative Medicine*. 13 (6), pp.459-468.
- Fife, B. Wright, E. (2000) The dimensionality of stigma: a comparison of its impact on the self of persons with HIV/AINDS and Cancer. *Journal of Health and Social Behaviour*, 41 (1), pp.50-67.
- Finch, J. (2007) Displaying Families. *Sociology*, 41 (1), pp.65-81.
- Fischler, C. (1988) Food, Self and Identity. *Social Science Information*, 27, pp.275-293.
- Flanagan, J. Holmes, S. (1999) Facing the issues of dependence: some implications from the literature for the hospice and hospice nurses. *Journal of Advancing Nursing*, 29 (38), pp.592-599.
- Fleming, A. (1999) Older men in contemporary discourses on ageing: absent bodies and invisible lives. *Nursing Inquiry*, 6, pp.3–8.
- Forman, W. Kitzes, J. Anderson, R. Sheehan, D. (2003) *Hospice and Palliative Care Issues Influences by Culture*. London: Jones and Bartlett Publishers International.
- Fox, S. (1990), The ethnography of humour and the problem of social reality. *Sociology*, 24, pp.431-446.

- Frank, A. (1995) *The wounded storyteller: body, illness and ethics*. London: The University of Chicago.
- Franklin, L. Ternest ed, B. Nordenfelt, L. (2006) Views on dignity of elderly nursing home residents. *Nursing Ethics*, 13 (2), pp.130-146.
- Franzoi, S. Kessenich, J. Sugrue, P. (1989) Gender differences in the experience of body awareness: an experiential sampling study. *Sex Roles*, 21 (7/8), pp.499-515.
- Franzoi, S. (1995) The body-as-object versus the body-as-process: gender differences and gender considerations. *Sex Roles*, 33 (5/6), pp.417-437.
- Fravel, D. Boss, P. (1992) An in-depth interview with the parents of missing children, In Gilgun, J. Doley, K. Handel, G. (eds) *Qualitative Methods in Family Research*. Newbury Park, CA: Sage.
- Freund P. (1990) The expressive body: a common ground for the sociology of emotions and health and illness. *Sociology of Health and Illness*, 12 (4), pp.452-477.
- Freund, P. (1998) Social performances and their discontents: the biopsychosocial aspects of dramaturgical stress. In G. Bendelow, and S. Williams (eds) *Emotions in Social Life: Critical Themes and Contemporary Issues*. London: Routledge.
- Frith, H. Harcourt, D. Fussell, A. (2007) Anticipating and altered appearance: women undergoing chemotherapy treatment for breast cancer. *European Journal of Oncology Nursing*, 11, pp.385-391.
- Froggatt, K. (2001) Life and death in English nursing homes: sequestration or transition?. *Ageing and Society*, 21 (3), pp.319-332.

- Gallagher, A. Li, S. Wainwright, P. Jones, I. Lee, D. (2008) Dignity in the care of older people: a review of the theoretical and empirical literature, *BMC Nursing*, 7 (18), viewed at 19 July 2010 <http://www.biomedcentral.com/1472-6955/7/11>
- Galvin, R. (2005) Researching the disabled identity: contextualising the identity transformations which accompany the onset of impairment. *Sociology of Health and Illness*, 27 (3), pp.393–413.
- Genoe, R. Dupuis, S. Keller, H. Martin, L. Cassolato, C. Edward, H. Honouring identity through mealtimes in families living with dementia. *Journal of Aging Studies*, 24, pp.181-193.
- Glaser, B. Strauss, A. (1965) *Awareness of Dying*. Chicago: Aldine Publishing Company.
- Giddens, A. (1991) *Modernity and self-identity*. Cambridge: Polity Press.
- Gilbert, K.R. (2001) Introduction: why are we interested in emotions? In Gilbert, K.R. (eds) *The Emotional Nature of Qualitative Research*. London: CRC.
- Gilbert, N. (2008) *Researching Social Life*. London: Sage.
- Gilleard, C. Higgs, P. (2000a) *Cultures of Ageing: Self, Citizen and the Body*. London: Prentice Hall.
- Gilleard, C. Higgs, P. (2010b) Aging without agency: Theorizing the fourth age. *Aging and Mental Health*, 14 (2), pp.121-128.
- Gilleard, C. Higgs, P. (2011) Ageing abjection and embodiment in the fourth age. *Journal of Aging Studies*, 25, pp. 135–142.

- Gilleard, C. Higgs, P. (2013) The fourth age and the concept of a 'social imaginary': A theoretical excursus. *Journal of Aging Studies*, 27, pp.368–376.
- Gimlin, D. (2006) The Absent Body Project: Cosmetic Surgery as a Response to Bodily Dys-appearance. *Sociology*, 40, pp.699-716.
- Glaser, B. Strauss, A. (1967) *The Discovery of the Grounded Theory*. New Jersey: Aldine Transaction.
- Gooldin, S. (2003) Fasting Women, Living Skeletons and Hunger Artists: Spectacles of Body and Miracles at the Turn of a Century. *Body and Society*, 9, pp.27-53.
- Good, M. Good, B. Schaffer, C. Lind, S. (1990) American oncology and the discourse on hope. *Culture, Medicine and Psychiatry*, 14, pp.59-79.
- Goffman, E. (1959) *The Presentation of Self in Everyday Life*. London: Penguin Books.
- Goffman, E. (1963) *Stigma: notes on the management of the spoiled identity*. New Jersey: Prentice-Hall Inc.
- Goffman, E. (1971) *Relations in Public*. London: Harper & Row, Publishers.
- Gomes B, Calanzani N, Curiale V, McCrone P, Higginson I., (2013a) Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers (Review). *The Cochrane Library*, 6, pp. 1-287.
- Gomes, B., Calanzani, N. Gysels, M. Hall, S. Higginson, I. (2013b) Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliative Care*, 12 (7), pp.1-13.

Gonçalves, F., Castro, S. (2001). Diagnosis disclosure in a Portuguese oncological centre. *Palliative Medicine*, 15, pp.35-41.

Gonçalves, J. Alvarenga, M. Silva, A. (2003) The Last Forty-Eight Hours of Life in a Portuguese Palliative Care Unit: Does it Differ from Elsewhere?. *Journal of Palliative Medicine*, 6 (6), pp.895-900.

Gonçalves, F. Cordero, A. Almeida, A. Cruz, A. Rocha, C. Feio, M. Silva, P. Barbas, S. Neves, S. (2012) A survey of the sedation practice of Portuguese palliative care teams. *Support Care Cancer*, 20, pp.3123–3127.

Gonçalves, F. Almeida, A. Antunes, C. Cardoso, M. Carvalho, M. Claro, M. Coimbra, F. Diniz, I. Fonseca, B. Fradique, E. Gonçalves, E. Gonçalves, F. Gonçalves, M. Magalhães, A. Pina, P. Pires, C. Silva, P. Silva, R. Silva, R. Tavares, F. Teixeira, L. (2013a) A Cross-Sectional Survey of the Activity of Palliative Care Teams in Portugal. *American Journal of Hospice and Palliative Care*, 30 (7), pp.648-651.

Gonçalves, F. Almeida, A. Antunes, C. Cardoso, M. Carvalho, M. Claro, M. Coimbra, F. Diniz, I. Fonseca, B. Fradique, E. Gonçalves, E. Gonçalves, F. Gonçalves, M. Magalhães, A. Pina, P. Pires, C. Silva, P. Silva, R. Silva, R. Tavares, F. Teixeira, L. (2013b) A cross-sectional survey of pain in palliative care in Portugal. *Support Care Cancer*, 21, pp.2033–2039.

Gonçalves, F. Almeida, A. Antunes, C. Cardoso, M. Carvalho, M. Claro, M. Coimbra, F. Diniz, I. Fonseca, B. Fradique, E. Gonçalves, E. Gonçalves, F. Gonçalves, M. Magalhães, A. Pina, P. Pires, C. Silva, P. Silva, R. Silva, R. Tavares, F. Teixeira, T.

(2014) Symptoms Other Than Pain in Palliative Care in Portugal. *American Journal of Hospice and Palliative Care*, pp. 1-6.

Gordon, D. Paci, E. (1997) Disclosure practices and cultural narratives: understanding concealment and silence around cancer in Tuscany, Italy. *Social Science and Medicine*, 44 (10), pp.1433-1452.

Goodrum, S. Keys, J. (2007) Reflections on two studies of emotionally sensitive topics: bereavement from murder and abortion. *International Journal of Social Research Methodology*, 10 (4), pp.249-258.

Gott, M. Seymour, J. Bellamy, G. Clark, D. Ahmedzai, S. (2004) Older people's views about home as a place of care at end of life. *Palliative Medicine*, 18, pp.460-467.

Gott, M. Small, N. Barnes, S. Payne, S. Seamark, D. (2008) Older people's views of a good death in heart failure: Implications for palliative care provision. *Social Science and Medicine*, 67, pp.1113–1121.

Grande, G. Stajduhar, K. Aoun, S. Toye, C. Funk, L. Addington-Hall, J. Payne, S. Todd, C. (2009) Supporting lay carers in end of life care: current gaps and future priorities. *Palliative Medicine*, 23, pp.339-344.

Gray, D. (1993) Perceptions of stigma: the parents of autistic children. *Sociology of Health and Illness*, 15 (1), pp.102-120.

Grønning I. Scambler, G. Tjora, A. (2013) From fatness to badness: The modern morality of obesity. *Health (London)*, 17 (3), pp.266–283.

Grosz, E. (1994) *Volatile Bodies: Toward a Corporeal Feminism*. Bloomington: Indiana University Press.

- Gross, N. (2005) The detraditionalization of intimacy reconsidered. *Sociological Theory*, 23 (3), pp.286-311.
- Guerrero, T.J. Naldini, M. (1996) Is the South so different? Italian and Spanish families in comparative perspective. *Working Papers from the International Project on Family Changes and Family Policies*, Mannheim Centre for European Social Research.
- Guillemin, M. Gillam, L. (2004) Ethics, Reflexivity, and "Ethically Important Moments" in Research. *Qualitative Inquiry*, 10 (2), pp. 261-280.
- Gurevich, M. Bishop, S. Bower, J. Malka, M. Nyhof-Young, J. (2004) (Dis) embodying gender and sexuality in testicular cancer. *Social Science and Medicine*, 58, pp.1597-1607.
- Hall, W. Callery, P. (2001) Enhancing the Rigor of Grounded Theory: Incorporating Reflexivity and Relationality. *Qualitative Health Research*, 11 (2), pp.257-272.
- Hakansson, J. Montgomery, H. (2003) Empathy as an interpersonal phenomenon. *Journal of Social and Personal Relationships*, 20, pp.267-284.
- Hammarstrom, G. Torres, S. (2010) Being, feeling and acting: a qualitative study of Swedish home-help care recipients' understandings of dependence and independence. *Journal of Aging Studies*, 24, pp.75-87.
- Hammersley, M. (2003) 'Analytics' are No Substitute for Methodology: A Response to Speer and Hutchby. *Sociology*, 37, pp.339-351.
- Harding, R. Higginson, I. (2003) What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliative Medicine*, 17, pp.63-74.

- Henley, N. (1973) The politics of touch. In Browd, P. (ed) *Radical Psychology*. London: Tavistock.
- Hewitt, J. (2007) Ethical components of researcher researched relationships in qualitative interviewing. *Qualitative Health Research*, 17 (8), pp.1149-1159.
- Hesketh, P. Batchelor, D. Golant, M. Lyman, G. Rhodes, N. Yardley, D. (2004) Chemotherapy-induced alopecia psychosocial impact and therapeutic approaches. *Support Care Cancer*, 12, pp.543–549.
- Hesse-Biber, S. Leavy, L. (2005) *The Practice of Qualitative Research*. Thousand Oaks, CA: Sage Publications.
- Herskovits, E. Mitness, L. (1994) Transgressions and sickness in old age. *Journal of Aging Studies*, 8 (3), pp.327-340.
- Higginson, I. Sarmiento, V. Calanzani, N. Benalia, H. Gomes, B. (2013) Dying at home - is it better: A narrative appraisal of the state of the science. *Palliative Medicine*, 0 (0), pp.1-7.
- Higgs, P. Leontowistch, M. Stevenson, F. Jones, I. (2009) Not just old and sick – the ‘will to health’ in later life. *Ageing and Society*, 29 (5), pp 687- 707.
- Hilton S, Emslie C, Hunt K, Chapple A, Ziebland S. (2009) Disclosing a cancer diagnosis to friends and family: a gendered analysis of young men and women’s experiences. *Qualitative Health Research*, 19, pp.744-54.
- Hochschild, A. (1979) Emotion work, feeling rules, and social structure. *American Journal of Sociology*, 85, pp.551–75.

- Hochschild, A. (1983) *The Managed Heart: Commercialization of Human Feeling*. Berkeley, CA: University of California Press.
- Hockey, J. James, A. (1993) *Growing Up and Growing Old: Ageing and Dependency in the Life Course*. London: Sage.
- Holder, H. (2003) Nursing management of nutrition in cancer and palliative care. *British Journal of Nursing*, 12 (11), pp.667-674.
- Hopkins, K. (2004) Food for life, love and hope: an exemplar of the philosophy of palliative care in action. *Nutrition Society*, 63, pp.427–429.
- Hopkinson, J. Wright, D. Corner, J. (2006) Exploring the experience of weight loss in people with advanced cancer. *Journal of Advanced Nursing*, 54 (3), pp.304-312.
- Hopkinson, J. and Corner, J. (2006) Helping patients with advanced cancer live concerns about eating: a challenge for palliative care professionals. *Journal of Pain and Symptom Management*, 31 (4), pp.293-305.
- Howarth, G. (2007) *Death and Dying: A Sociological Introduction*. Cambridge: Polity.
- Hubbard, G. Backett-Milburn, K. Kemmer, D. (2001) Working with emotion: issues for the researcher in fieldwork and teamwork. *Social Research Methodology*, 4 (2), pp.119-137.
- Hudson, P. Aranda, S. Kristjanson, L. (2004) Meeting the Supportive Needs of Family Caregivers in Palliative Care: Challenges for Health Professionals. *Journal of Palliative Medicine*, 7 (1), pp.19-25.

Hudson, P. Payne, S. (2011) Family Caregivers and Palliative Care: Current Status and Agenda for the Future. *Journal of Palliative Medicine*, 14 (7), pp.864-869.

Hughes, N. Neal. R. (2000) Adults with terminal illness: a literature review of their needs and wishes for food. *Journal of Advanced Nursing*, 32 (5), pp.1101-1007.

Hughes, B. (2009) Wounded/monstrous/abject: a critique of the disabled body in the sociological imaginary. *Disability and Society*, 24:4, 399-410.

Hurd Clarke, L. (2000) Older Women's Body Image and Embodied Experience: An Exploration. *Journal of Women and Aging*, 12 (3-4), pp.77-97.

Hurd Clarke, L. (2001) Older women's bodies and the self: the construction of identity in later life. *Canadian Review of Sociology*, 38 (4), pp.441-464.

Hurd Clarke, L. (2002) Older women's perceptions of ideal body weights: the tensions between health and appearance motivations for weight loss. *Ageing and Society*, 22, pp.751-773.

Hurd Clarke, L. Griffin, M. (2007a) The body natural and the body unnatural: Beauty work and aging. *Journal of Aging Studies*, 21, pp.187-201.

Hurd Clarke, L. Griffin, M. (2007b) Becoming and being gendered through the body: older women their mothers and body image. *Ageing and Society*, 27 (5), pp.701-718.

Hurd Clarke, L. Griffin, M. PACC Research Team. (2008) Failing Bodies: Body Image and Multiple Chronic Conditions in Later Life. *Qualitative Health Research*, 18 (8), pp.1084-1095.

Hurd Clarke, L. Griffin, M. (2008) Visible and invisible ageing: beauty work as a response to ageism. *Ageing and Society*, 28 (5), pp.653-674.

Hurd Clarke, L. Griffin, M. Maliha, K. (2009) Bat wings, bunions, and turkey wattles: body transgressions and older women's strategic clothing choices. *Ageing and Society*, 29 (5), pp 709-726.

Hurd Clarke, L. Bundon, A. (2009) From 'The Thing to Do' to 'Defying the Ravages of Age': Older Women Reflect on the Use of Lipstick, *Journal of Women and Aging*, 21 (3), pp.198-212.

Hurd Clarke, L. Korotchenko, A. (2010) Shades of grey: to dye or not to dye one's hair in later life. *Ageing and Society*, 30 (6), pp. 1011–1026.

Hurd Clarke, L. Korotchenko, A. (2011) Aging and the Body: A Review, *Canadian Journal on Aging*, 30 (3), pp 495-510.

Hurd Clarke, L. Korotchenko, A. Bundon, A. (2012) 'The calendar is just about up': older adults with multiple chronic conditions reflect on death and dying. *Ageing and Society*, 32 (8), pp.1399 – 1417.

Hurd Clarke, L. Bennett, E. (2013a) 'You learn to live with all the things that are wrong with you': gender and the experience of multiple chronic conditions in later life. *Ageing and Society*, 33 (2), pp.342 360.

Hurd Clarke, L. Bennett, E. (2013b) Constructing the moral body: Self-care among older adults with multiple chronic conditions, *Health (London)*, 17 (3), pp.211–228.

Hunt, M. (1991) Being friendly and informal: reflected in nurses', terminally ill patients' and relatives' conversations at home. *Journal of Advanced Nursing*, 16, pp.929-938.

- Hunt, R. (1997) Place of death of cancer patients: choice versus constraint. *Progress in Palliative Care*, 5, pp.238-241.
- Hutchinson, S. Wilson, M. Wilson, H. (1994) Benefits of participating in research interviews. *IMAGE: Journal of Nursing Scholarship*, 26 (2), pp.161-164.
- Hýden, L-C. Orulv, L. (2009) Narrative and identity in Alzheimer's disease: A case study. *Journal of Aging Studies*, 23, pp.205-214.
- Hyman, H. (1954) *Interviewing in Social Research*. Chicago: The University of Chicago Press.
- Ingleton, C. Davies, S. (2007) Mixed methods for evaluation research. In Addington-Hall, J. (ed) *Research Methods in Palliative Care*. Oxford: Oxford University Press.
- Jacelon, C. Henneman, E. (2004) Profiles in dignity: perspectives on nursing and critically ill older adults. *Critical Care Nurse*, 24, pp.30-35.
- Jacelon, C. (2004) Managing personal integrity: the process of hospitalization for elders. *Journal of Advanced Nursing*, 46 (5), pp.549-557.
- Jacelon, C. Connelly, T. Brown, R. Proulx, K. Vo, T. (2004) A concept analysis of dignity for older adults. *Journal of Advanced Nursing*, 48 (1), pp.76-83.
- Jacobson, N. (2007) Dignity and health: a review. *Social Science and Medicine*, 64, pp.292-302.
- James, N. (1989) Emotional Labour: Skill and Work in the Social Regulation of Feelings. *The Sociological Review*, 37 (1), pp.15-42.

- James, N. (1992) Care = organisation + physical labour + emotional labour. *Sociology of Health and Illness*, 14 (4), pp.487-509.
- James, N. Field, D. (1992) The routinization of hospice: charisma and bureaucratization. *Social Science and Medicine*, 34 (12), pp.1363-1375.
- James, I. Andershed, B. Ternestedt, B. (2007) A family's beliefs about cancer, dying, and death in the end of life. *Journal of Family Nursing*, 13 (2), pp.226-252.
- Jamieson, L. (1998) *Intimacy. Personal Relationships in Modern Societies*. Cambridge: Polity Press.
- Jervis, L. (2001) The pollution of incontinence and the dirty work of caregiving in a U.S. nursing home. *Medical Anthropology Quarterly*, 15 (1), pp.84-89.
- Johnson, J. (2002) In-depth Interviewing. In Gubrium, J. Holstein, J. (eds) *Handbook of Interview Research: Context & Method*, Thousand Oaks, CA: Sage Publications.
- Johnson, B. Clarke, J.M. (2003) Collecting sensitive data: the impact on researchers, *Qualitative Health Research*. 13, pp.421-434.
- Jones, E., Farina, A., Hastorf, A., Markus, H., Miller, D. and Scott, R. (1984) *Social Stigma*. New York: W.H. Freeman and Company.
- Jorgensen, D. (1989) *Participant Observation*. London: Sage.
- Jurado Guerrero, T. Naldini, M. (1996) Is the South so different? Italian and Spanish Families in Comparative Perspective. *Working Papers from the International Project on Family Changes and Family Policies*, Research Department I, Mannheim Centre for European Social Research.

- Jutel, A. (2005) Weighing Health: The Moral Burden of Obesity. *Social Semiotics*, 15:2, 113-125.
- Karamessini, M. (2008) Continuity and change in the southern European social model. *International Labour Review*, 147 (1) pp. 43-70.
- Karner, T. (1998) Professional caring homecare workers as fictive kin. *Journal of Aging Studies*, 12, pp.69-82.
- Kehl, K.A. (2006) Moving toward peace: an analysis of the concept of a good death. *American Journal of Hospice and Palliative Care*, 23 (4), pp.277 -286.
- Kellehear, A. (1984) Are we a death-denying society? A sociological review. *Social Science and Medicine*, 18 (9), pp.713-723.
- Kellehear, A. (1990) *Dying of Cancer: the Final Year of Life*. Reading: Hardwood Academic Publishers.
- Kellehear, A. (2008) Dying as a social relationship: A sociological review of debates on the determination of death. *Social Science and Medicine*, 66, pp.1533-1544.
- Kellehear, A. (2009) What the social and behaviour studies say about dying. In Kellehear, A. (ed) *The Study of Dying: From Autonomy to Transformation*, Cambridge: Cambridge University Press, pp.1-26.
- Kellehear, A. Pugh, E. Atter, L. (2009) Home away from home? A case study of bedside objects in a hospice. *International Journal of Palliative Nursing*, 15 (3), pp.148-52.
- Kelly M. (1992) Self, identity and radical surgery. *Sociology of Health and Illness*, 14 (3), pp.390-415.

- Kelly M. Field. D. (1996) Medical sociology, chronic illness and the body. *Sociology of Health and Illness*, 18 (2), pp.241-257.
- Kelly M. Field D. (1997) Body image and sociology: a reply to Simon Williams. *Sociology of Health and Illness*, 19 (3), pp.359-366.
- Kelly, B. Burnett, P. Pelusi, D. Badger, S. Varghese, F. Robertson, M. (2002) Terminally ill cancer patients' wish to hasten death. *Palliative Medicine*, 16 (4), pp.339-345.
- Kelly, D. (2009) Changed men: the embodied impact of prostate cancer. *Qualitative Health Research*, 19 (2), pp.151-163.
- King, D. Quill, T. (2006) Working with Families in Palliative Care: One Size Does Not Fit All. *Journal of Palliative Medicine*, 9 (3), pp.704-715.
- Kitwood, T. Bredin, K. (1992) Towards a theory of dementia care: personhood and well-being. *Ageing and Society*, 12, pp.269-287.
- Kitwood, T. (1997) *Dementia Reconsidered: the Person Comes First*. Buckingham: Open University Press.
- Kitzinger, J. Kitzinger, C. (2013) The 'window of opportunity' for death after severe brain injury: family experiences. *Sociology of Health and Illness*, 35 (7), pp.1095–1112.
- Klinkenberg, M. Willems, D. Onwuteaka-Philipsen, B. Deeg, D. Wal, G. (2004) Preferences in end of life care of older persons: after-death interviews with proxy respondents. *Social Science and Medicine*, 59, pp. 2467–2477.

- Kontos, P. (2003) The painterly hand: embodied consciousness and Alzheimer's disease. *Journal of Aging Studies*, 17, pp.151-170.
- Kontos, P. (2006). Embodied selfhood: An ethnographic exploration of Alzheimer's disease. In A. Leibing, & L. Cohen (Eds.), *Thinking about dementia: Culture, loss and the anthropology of senility*. New Jersey: Rutgers University Press.
- Kontos, P. Naglie, G. (2007) Bridging theory and practice: imagination, the body, and person-centred dementia care. *Dementia*, 6 (4), pp.549-569.
- Kramer, B. Boelk, A. Auer, C. (2006) Family Conflict at the End of Life: Lessons Learned in a Model Program for Vulnerable Older Adults. *Journal of Palliative Medicine*, 9 (3), pp.791-801.
- Kubler-Ross, E. (1969) *On Death and Dying*. New York: Macmillan.
- Kubler-Ross, E. (1975) *Death: the Final Stage of Grow*. Englewood-Cliff: Prentice.
- Kwan, S. Competing Motivational Discourses for Weight Loss: Means to Ends and the Nexus of Beauty and Health. *Qualitative Health Research*, 19 (9), pp.1223-1233.
- Lalor, J. Begley, C. Devane, D. (2006) Exploring painful experiences: impact of emotional narratives on members of a qualitative research team. *Journal of Advanced Nursing*, 56 (6), pp.607-616.
- La Fontaine, J. (1985) Person and individual: some anthropological reflections, In M. Carrithers, S. Collins and S. Lukes (eds) *The Category of the Person*. Cambridge: Cambridge University Press, pp.123-140.

- Lamb, S. (2014) Permanent personhood or meaningful decline? Toward a critical anthropology of successful aging. *Journal of Aging Studies*, 29, pp.41–52.
- Lau, U. van Niekerk, A. (2011) Restorying the Self: An Exploration of Young Burn Survivors' Narratives of Resilience. *Qualitative Health Research*, 21 (9), pp.1165-1181.
- Lawton, J. (1998) Contemporary hospice care: the sequestration of the unbounded body and dirty dying. *Sociology of Health and Illness*, 20 (2), pp.121-143.
- Lawton, J. (2000) *The Dying Process: Patients' Experiences of Palliative Care*. London: Routledge.
- Lawton, J. (2001) Gaining and maintaining ethical concerns raised in a study of dying patients. *Qualitative Health Research*, 11 (5), pp.693-705.
- Lawton, J. (2003) Lay experiences of health and illness: past research and future agendas. *Sociology of Health and Illness*, 25, pp.23-40.
- Leder, D. (1990) *The Absent Body*. Chicago, IL: University of Chicago Press.
- Lee, R. (1993) *Doing Research on Sensitive Topics*. London: Sage.
- Lee, R. (2008) Modernity, Mortality and Re-Enchantment: The Death Taboo Revisited. *Sociology*, 42 (4), pp.745–759.
- Lewis, A. Silver, C. (2007) *Using Software in Qualitative Research*. Sage: London.
- Li, S. (2002) *Symbiotic Niceness: A Study of Psychosocial Care in Palliative Care Settings*, Unpublished PhD Thesis, Goldsmith's College, University of London.
- Li, S. (2004) 'Symbiotic niceness': constructing a therapeutic relationship in psychosocial palliative care. *Social Science and Medicine*, 58, pp.2571–2583.

- Li, S. Arber, A. (2006) The Construction of Troubled and Credible Patients: A Study of Emotion Talk in Palliative Care Settings. *Qualitative Health Research*, 16, pp.27-46.
- Li, S. Seale, C. Acquiring a Sociological Identity: An Observational Study of a PhD Project. *Sociology*, 42, pp.987-1002.
- Liamputtong, P. (2007) *Researching the Vulnerable*. London: Sage.
- Little, M. Jordens, C. Paul, K. Montgomery, K. Philipson, B. (1998) Liminality: a major category of the experience of cancer illness. *Social Science and Medicine*, 47 (10), pp.1485-1494.
- Long, S. (2004) Cultural scripts for a Good Death in Japan and the United States: similarities and differences. *Social Science and Medicine*, 58, pp.913–928.
- Long, S. Long, B. (1982) Curable cancers and fatal ulcers: attitudes toward cancer in Japan. *Social Science and Medicine*, 16, pp.2101-2108.
- Lopes, A. (2006) *Welfare arrangements, safety, nets and familial support for the elderly in Portugal*, Unpublished PhD Thesis. London: London School of Economics.
- Lowes, L. Gill, P. (2006) Participants' experiences of being interviewed about an emotive topic. *Journal of Advanced Nursing*, 55 (5), pp.587-594.
- Lowton, K. (2004) Only when I cough? Adult's disclosure of cystic fibrosis, *Qualitative Health Research*. 14, pp.167-186.
- Lowton, K. (2009) 'A bed in the middle of nowhere': Parents' meaning of place of death for adults with cystic fibrosis. *Social Science and Medicine*, 69, pp.1056-1062.

- Lunceford, B. (2010) Clothes Make the Person? Performing Gender Through Fashion, *Communication Teacher*, 24 (2), pp.63-68.
- Lupton, D. (1994) Food, memory and meaning: the symbolic and social nature of food and events, *The Sociological Review*. 42 (4), pp.664-685.
- Lupton, D. (1994) *Medicine as Culture: Illness, Disease and the Body in Western Societies*. London: Sage.
- Lupton, D. (1996) *Food, the body and the self*. London: Sage.
- MacRae, H. (1999) Managing courtesy stigma: the case of Alzheimer's disease. *Sociology of Health and Illness*, 21 (1), pp. 54-70.
- McCarthy, D. (2003) Rethinking nutritional support for individuals with cancer cachexia. *Biological Research for Nursing*, 5 (1), pp.3-17.
- Mak, J. Clinton, M. (1999) Promoting a Good Death: an agenda for outcomes research - a review of the literature. *Nursing Ethics*, 6 (2), pp.97-106.
- Mamo, L. (1999) Death and dying: confluences on emotion and awareness. *Sociology of Health and Illness*, 21 (1), pp.13-36.
- Manderson, L. (2005) Boundary breaches: the body, sex and sexuality after stoma surgery. *Social Science and Medicine*, 61, pp.405-415.
- Mauss, M. (1979) 'Body techniques' in Mauss, M. (eds) *Sociology and Psychology: Essays*. London: Routledge and Kegan Paul, pp.95-123.
- Mason, J. (2004) Personal narratives, relational selves: residential histories in the living and living and telling. *The Sociological Review* 52 (2): 162-179.

- Mathieson, C. Stam, H. (1995) Renegotiating identity: cancer narratives. *Sociology of Health and Medicine*, 17 (3), pp.283-306.
- Marvasti, A. (2004) *Qualitative Research in Sociology*. London: Sage.
- McClement, S. Degner, L, Harlos, M. (2003) Family Beliefs Regarding the Nutritional Care of a Terminally Ill Relative: A Qualitative Study. *Journal of Palliative Medicine*, 6 (5), pp.737-748.
- McDonnel, A. Lloyd, M. Read, S. (2000) Practical considerations in case study research: the relationship between methodology and process. *Journal of Advanced Nursing*, 32 (2), pp.383-390.
- McGarvey, E. Baum, L. Pinkerton, R. And Rogers, L. (2001) Psychological sequelae and alopecia among women with cancer. *Cancer Practice*, 9 (6), pp.283-289.
- McInerkey, F. (1992) Provision of food and fluids in terminal care: a sociological analysis. *Social Science and Medicine*, 34 (2), pp.1271-1276.
- McKenzie, H. Crouch, M. (2004) Discordant feelings in the lifeworld of cancer survivors. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 8 (2), pp.139-157.
- McNamara, B. Waddel, C. Colvin, M. (1994) The institutionalization of the Good Death. *Social Science and Medicine*, 39 (11), pp.1501-1508.
- McNamara, B. Waddel, C. Colvin, M. (1995) Threats to the good death: the cultural context of stress and coping among hospice nurses. *Sociology of Health and Medicine*, 17 (2), pp.222-244.

- McNamara, B. (2001) *Fragile Lives: death, dying and care*. Buckingham: Open University Press.
- McNamara, B. (2004) Good enough death: autonomy and choice in Australian palliative care. *Social Science and Medicine*, 58, pp.929-938.
- McPherson, C. Addington-Hall, J. (2003) Judging the quality of care at the end of life: can proxies provide reliable information?. *Social Science and Medicine*, 56, pp. 95–109.
- McPherson, C. Wilson, K.G. Murray, M.A. (2007) Feeling like a burden: exploring the perspectives of patients at the end of life. *Social Science and Medicine*, 64, pp.417-427.
- Meerabeau, L. Page, S. (1998) Getting the job done: emotion management and cardiopulmonary resuscitation in nursing. In Bendelow, G. and Williams, S. (eds) *Emotions in Social Life: Critical Themes and Contemporary Issues*. London: Routledge.
- Mellor, P. (1993) Death in high modernity: the contemporary presence and absence of death. In D. Clark (ed) *The Sociology of Death*. Oxford: Blackwell Publishers.
- Mellor, S. Shilling, C. (1993) Modernity, self-identity and the sequestration of death. *Sociology*, 27 (3), pp.411-431.
- Merleau-Ponty, M. (1962) *The Phenomenology of Perception*. London: Routledge and Kegan Paul.
- Melrose, M. (2002) Labour pains: some considerations on the difficulties of researching juvenile prostitution. *International Journal of Social Research Methodology*, 5 (4), pp.33-351.

- Miles, S. (1987) Futile feeding at the end of life: family virtues and treatment decisions. *Theoretical Medicine*, 8, pp.293-302.
- Mitteneess,L. Barker, J. (1995) Stigmatizing a normal condition: urinary incontinence in late life. *Medical Anthropology Quarterly*, 9 (2), pp.188-210.
- Miyafi, N. (1993) The power of compassion: truth-telling among American doctors in the case of dying patients. *Social Science and Medicine*, 36 (3), pp.249-264.
- Moore, L. Miller, M. (1990) Initiating research with doubly vulnerable populations. *Journal of Advanced Nursing*, 30 (5), pp.1034-1040.
- Montez, J.K. Karner, T.X. (2005) Understanding the diabetic body-self. *Qualitative Health Research*, 15 (8), pp.1086-1104.
- Moreno, L. (2006). The model of social protection in Southern Europe: Enduring characteristics? *Revue francaise des affaires sociales*, 5, pp.73–95.
- Moss, S. Moss, M. (2007) Being a man in long term care. *Journal of Aging Studies*, 21, pp.43–54.
- Moss, S. Moss, M. Kilbride, J. Rubinstein, R. (2007) Frail men's perspectives on food and eating. *Journal of Aging Studies*, 21, pp.314–324.
- Moyle, W. (2002) Unstructured interviews: challenges when participants have a major depressive illness. *Journal of Advanced Nursing*, 39 (3), pp.266-273.
- Mulkay, M. (1993) Social death in Britain. In D. Clark (ed) *The Sociology of Death*. Oxford: Blackwell Publishers.

Munstedt, K. Manthey, N. Sachsse, S. Vahrson, H. (1997) Changes in self-concept and body image during alopecia induced cancer chemotherapy. *Support Care Cancer*, 5, pp.139-143.

Murcott, A. (1982) The cultural significance of food and eating. *Proceeding of the Nutrition of Society*, 41, pp.203-210.

Murcott, A. (1983) Introduction. In Murcott, A. (ed) *The Sociology of Food and Eating*. Albershot: Gower Publishing Company Limited.

Murphy, R. Scheer, J. Murphy, Y. Mack, R (1988) Physical disability and social liminality: a study of the rituals of adversity. *Social Science and Medicine*, 26 (2), pp.235-242.

Murphy, E. Dingwall, R. (2001) The ethics of ethnography. In Atkinson, P. (ed) *Handbook of Ethnography*. London: Sage.

Mwaria, C. (1990) The concept of self in the context of crisis: a study of families of the severely brain-injured. *Social Science and Medicine*, 30 (8), pp.889-893.

Navon, L. Morag, A. (2004) Liminality as biographical disruption: unclassifiability following hormonal therapy for advanced prostate cancer. *Social Science and Medicine*, 58, pp.2337-2347.

Netleton, S. (2006) *The Sociology of Health and Illness*. Cambridge: Polity Press.

Neto, I. Marques, A Gonçalves, E. Salazar, H. Capelas, M. Tavares, J. Sapeta, A. (2010) Palliative care development is well under way in Portugal. *European Journal of Palliative Care*, 17 (6), pp.278-281.

- Nicholson, C. Meyer, J. Flatley, M. Holman, C. Lowton, K. (2012) Living on the margin: understanding the experience of living and dying with frailty in older age. *Social Science and Medicine*, 75, pp.1426-1432.
- Nijhof, G. (1995) Parkinson's Disease as a problem of shame in public appearance. *Sociology of Health and Illness*, 17 (2), pp.193-205.
- Nordenfelt, L. (2004) The varieties of dignity, *Health Care Analysis*, 12, pp.69-81.
- Nordenfelt, L. Edgar, A. (2005) The four notions of dignity, *Quality in Ageing: Policy, Practice and Research*, 6 (1), pp.17-21.
- Nordenfelt, L. (2009) *Dignity in Care for Older People*. Oxford, Blackwell Publishing.
- Norlyk, A. Harder, I. (2010) What Makes a Phenomenological Study Phenomenological? An Analysis of Peer-Reviewed Empirical, *Qualitative Health Research*, 20, pp.420-431.
- Nunokoosing, K. (2005) The problems with interviews. *Qualitative Health Research*, 15 (5), pp.698-706.
- Oleson, V. Bone, D. (1998) Emotions in rationalizing organizations: conceptual notes from professional nursing in the USA. In Bendelow, G. and Williams, S. (eds) *Emotions in Social Life: Critical Themes and Contemporary Issues*. London: Routledge.
- Oliffe, J. (2005) Constructions of masculinity following prostatectomy-induced impotence. *Social Science and Medicine*, 60, pp.2249-2259.
- Oliffe, J. (2006) Embodied masculinity and androgen deprivation therapy. *Sociology of Health and Illness*, 28 (4), pp.410-432.

- Öhman, M. Söderberg, S. (2004) The Experiences of Close Relatives Living with a Person with Serious Chronic Illness, *Qualitative Health Research*, 14 (3), pp.396-410.
- Payne, S. Hillier, R. Langley-Evans, A. Roberts, T. (1996a) Impact of witnessing death on hospice patients. *Social Science and Medicine*, 43 (12), pp.1785-1794.
- Payne, S. Langley-Evans, A. Hillier, R. (1996b) Perceptions of a 'good' death: a comparative study of the views of hospice staff and patients. *Palliative Medicine*, 10, pp.307-312.
- Payne, S. (1997) Selecting and approach and design in qualitative research. *Palliative Medicine*, 11, pp.249-252.
- Payne, S. (2007) Qualitative methods of data collection and analysis. In Addington-Hall, J. Bruera, E. Higginson, I. Payne, S. (eds) *Research Methods in Palliative Care*. Oxford: Oxford University Press.
- Payne, G. Williams, M. (2005) Generalization in Qualitative Research. *Sociology*, 39 (2), pp.295–314.
- Peake, S. Manderson, L. (2003) The constrains of a normal life: the management of urinary incontinence by middle aged women. *Women and Health*, 37 (3), pp. 37-51.
- Peake, S. Manderson, L. Potts, H. (1999) Part and parcel of being women: female urinary incontinence and constructions of control. *American Anthropology Quarterly*, 13 (3), pp.267-285.
- Peräkylä, A., 2008. Reliability and Validity in Research Based on Naturally Occurring Social Interaction. In Silverman, D. (ed). *Qualitative Research: Theory, Method and Practice*, Los Angeles, London, New Delhi, Singapore: Sage Publications.

- Plazer, H. James, T. (1997) Methodological issues conducting sensitive research on lesbian and gay men's experience of nursing care. *Journal of Advanced Nursing*, 25, pp.626-633.
- Poole, K. Froggatt, K. (2002) Loss of weight and loss of appetite in advanced cancer: a problem for the patients, the carer, or the health professional? *Palliative Medicine*, 16, pp.499-506.
- Pound, P. Gompertz, P. Ebrahim, S. (1998) Illness in the context of older age: the case of stroke. *Sociology of Health and Illness*, 20, (4), pp.489-506.
- Prentice, D. Carranza, E. (2002) What women and men should be, shouldn't be, are allowed to be, and don't have to be: The contents of prescriptive gender stereotypes. *Psychology of Women Quarterly*, 26 (5), pp.269-281.
- Proot, I. Abu-Saad, H. Crebolder, H. Goldsteen, M. Luker, K. Widdershoven, G. (2003) Vulnerability of family caregivers in terminal palliative care at home; balancing between burden and capacity. *Scandinavian Journal of Caring Sciences*, 17, pp.113–121.
- Proulx, K. Jacelon, C. (2004) Dying with dignity: The good patient versus the Good Death. *American Journal of Hospice and Palliative Care*, 21, pp.116-120.
- Radley A. (1989) Style, discourse and constraint in adjusting to chronic illness. *Sociology of Health and Illness*, 11 (3), pp.230-252.
- Rager, K. (2005) Self-care and the qualitative researcher: when collecting data can break your heart. *Educational Researcher*, 34 (4), pp.23-27.

- Raijmakers, N. Clark, J. van Zuylen, L. Allan, S. van der Heide, A. (2013) Bereaved relatives' perspectives of the patient's oral intake towards the end of life: A qualitative study. *Palliative Medicine*, 27 (7), pp.665–672.
- Ramcharan, P. Cutcliffe, J. (2001) Judging the ethics of qualitative research: considering the ethics as process model. *Health and Social Care in the Community*, 9 (6), pp.358-366.
- Read, T. Wuest, J. (2007) Daughters Caring for Dying Parents: A Process of Relinquishing. *Qualitative Health Research*, 17 (7), pp.932-944.
- Reid, J. McKenna, H. Fitzsimons, D. McCance, T. (2009) The experience of cancer cachexia: a qualitative study of advanced cancer patients and their family members. *International Journal of Nursing Studies*, 46, pp.606-616.
- Reher, D. (1998) Family ties in Western Europe: persistent contrasts. *Population and Development Review*, 24 (2), pp.203-234.
- Renzetti, C. Lee, R. (1993) *Researching Sensitive Topics*. London: Sage.
- Resende, A. (2009) *Alimentar no final da vida*. Unpublished Master Thesis, Lisbon: Universidade Aberta.
- Ribeiro, O. Paúl, C. Nogueira, C. (2007) Real men, real husbands: Caregiving and masculinities in later life. *Journal of Aging Studies*, 21, pp.302–313.
- Richards, H.M. Schwartz, L.J. (2002) Ethics of qualitative research: are there special issues for health services research? *Family Practice*, 19, pp.135-139.

- Rich, E. (2006) Anorexic dis (connection): managing anorexia as an illness and an identity. *Sociology of Health and Illness*, 28 (3), pp. 284–305.
- Rich, E. (2011) 'I see her being obese!': Public pedagogy, reality media and the obesity crisis. *Health (London)*, 15 (3), pp.3-21.
- Rietjens, J. Hauser, J. van der Heide, A. Emanuel, L. (2007) Having a difficult time leaving: experiences and attitudes of nurses with palliative sedation. *Palliative Medicine*, 21, pp.643–649.
- Rodriquez, J. (2011) It's a dignity thing: Nursing home care workers use of emotions, *Sociological Forum*, 26 (2), pp.265-286.
- Romozmovits, L. Ziebland, S. (2004) Expressions of loss of adulthood in the narratives of people with colorectal cancer. *Qualitative Health Research*, 14 (2), pp.187-203.
- Rosman, S. (2004) Cancer and stigma: experience of patients with chemotherapy-induced alopecia. *Patient Education and Counselling*, 52 (3), pp.333-339.
- Rosser, C. Harris, C (1995) *The Family and Social Change: a study of family and kinship in a South Wales town*. London: Routledge and Kegan Paul.
- Rozario, P. Derienzis, D. (2009) 'So forget how old I am!' Examining age identities in the face of chronic conditions. *Sociology of Health and Illness*. 31 (4), pp.540–553.
- Ryen, A. (2004) Ethical issues. In Seale, C. et al. (ed) *Qualitative Research Practice*. London: Sage.
- Sabat, S. Harré, T. (1992) The Construction and Deconstruction of Self in Alzheimer's Disease. *Ageing and Society*, 12, pp.443-461.

Sanders, C. Donovan, J. Dieppe, P. (2002) The significance and consequences of having painful and disabled joints in older age: co-existing *accounts* of normal and disrupted biographies. *Sociology of Health and Illness*, 24 (2), pp.227-253.

Sandelowski, M. (1996) Focus on qualitative methods - one is the liveliest number: the case orientation of qualitative research. *Research in Nursing and Health*, 19, pp.525-529.

Sandelowski, M. (2004) Using qualitative research. *Qualitative Health Research*, 14 (10), pp.1366-1386.

Sandman, L. (2002) What's the use of human dignity within palliative care?. *Nursing Philosophy*, 3, pp.177-181.

Sanders, S. Power, J. (2009) Roles, responsibilities and relationships among older husbands caring for wives with progressive dementia and other chronic conditions. *Health and Social Work*, 34 (1), pp.41-51.

São Jose, J. Teixeira, A. (2013) In the 'ethical crossroads' of ethnography: observing the care encounter at the ender's home. In Paoletti, I. Tomás, M. Menéndez, M. (eds) *Practice of Ethics: an empirical approach to ethics in social science research*, Newcastle: Cambridge Scholar Publishing.

Scambler, G. Hopkins, A. (2008) Being epileptic: coming to terms with stigma. *Sociology of Health and Illness*, 8 (1), pp.26-43.

Scambler, G. (2009) Health-related stigma. *Sociology of Health and Illness*, 31 (3), pp.441-455.

- Scheper-Hughes, N. Locke, M. (1987) The Mindful Body. A Prolegomenon to Future Work in Medical Anthropology. *Medical Anthropology Quarterly*, 1 (1), pp.6–41.
- Schneider, J. Conrad, P. (1980) In the closet with illness: epilepsy, stigma potential and information control. *Social Problems*, 28 (1), pp.32-44.
- Seale, C. (1991a) Death from cancer and death from other causes: the relevance of the hospice approach. *Palliative Medicine*, 5, pp.12-19.
- Seale, C. (1991b) Communication and awareness about death: a study of a random sample of dying people. *Social Science and Medicine*, 32 (8), pp.943-952.
- Seale, C. (1991c) A comparison of hospice and conventional care. *Social Science and Medicine*, 32 (2), pp.147-152.
- Seale, C. (1995a) Dying alone. *Sociology of Health and Illness*, 17 (3), pp.376-392.
- Seale, C. (1995b) Heroic death. *Sociology*, 29 (4), pp.597-613.
- Seale, C. Addington-Hall, J. (1994) Euthanasia: why people want to die earlier. *Social Science and Medicine*, 39 (5), pp.647-684.
- Seale, C. Addington-Hall, J. (1995) Euthanasia: the role of good care. *Social Science and Medicine*, 40 (5), pp.581-587.
- Seale, C. Addington-Hall, J. McCarthy, M. (1997) Awareness of dying: prevalence, causes and consequences. *Social Science and Medicine*, 45 (3), pp.477-484.
- Seale, C. Kelly, M. (1997a) A comparison of hospice and hospital care for people who die: views of the surviving spouse. *Palliative Medicine*, 11, pp.93-100.

- Seale, C. Kelly, M. (1997b) A comparison of hospice and hospital care for the spouses of people who die. *Palliative Medicine*, 11, pp.101-106.
- Seale, C. (1998) *Constructing Death: the Sociology of Dying and Bereavement*. Cambridge: Cambridge University Press.
- Seale, C. (1999) *Quality of Qualitative Research*. London: Sage.
- Seale, C. (2000) Changing patterns of death and dying. *Social Science and Medicine*, 51, pp.917-930.
- Seale, C. (2004) Media constructions of dying alone: a form of bad death. *Social Science and Medicine*, 58, pp.967–974.
- Seale, C. (2009) Hastening death in end-of life care: A survey of doctors. *Social Science and Medicine*, 69, pp.1659-1666.
- Seale, C. (2010) Continuous deep sedation in medical practice: a descriptive study. *Journal of Pain and Symptom Management*, 39 (1), pp.44-53.
- Secker, J. Hill, R. Vileneau, L. Parkman, S. (2003) Promoting independence: but promoting what and how? *Ageing and Society*, 23 (3), pp.375-391.
- Seymour, W. (1998) *Remaking the body: rehabilitation and change*. London: Routledge.
- Seymour, J. Clark, D. (1998) Phenomenological approaches to palliative care research. *Palliative Medicine*, 12, pp.127–131.
- Seymour, J. (1999) Revisiting medicalisation and natural death. *Social Science and Medicine*, 49, pp.691-704.

- Seymour, J. and Skilbeck, C. (2002) Ethical considerations in researching user views. *European Journal of Cancer Care*, 11, pp.215-219.
- Seymour, J. (2001) *Critical Moments – Death and Dying in Intensive Care*. Buckingham: Open University Press.
- Seymour, J. (2007) Ethnography. In Addington-Hall, J. (ed) *Research Methods in Palliative Care*. Oxford: Oxford University Press.
- Seymour, J. Payne, S. Reid, D. Sargeant, A. Skilbeck, J. Smith, P. (2005) Ethical and methodological issues in palliative care studies. *Journal of Research in Nursing*, 10 (2), pp.169-188.
- Seymour, J. Janssens, R. Broeckaert, B. (2007a) Relieving suffering at the end of life: practitioners' perspectives of palliative sedation from three European countries. *Social Science and Medicine*, 64, pp.1679-1691.
- Seymour, J. Payne, S. Chapman, A. Holloway, M. (2007b) Hospice or home? Expectations of end of life care among white and Chinese older people in the UK, *Sociology of Health and Illness*, 29 (6), pp.872-890.
- Silva, M. (1995) *Ethical Guidelines in the Conduct, Dissemination and Implementation of Nursing Research*. Washington, DC: American Nurses Publishing.
- Silverman, D. (2005) *Doing Qualitative Research*. London: Sage.
- Sinding, C. Wiernikoski, J. (2008) Disruption foreclosed: older women's cancer narratives, *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 12 (3), pp.389-411.

- Sharp, K. (1998) The case for case studies in nursing research: the problem of generalization. *Journal of Advanced Nursing*, 27, pp.785-789.
- Sheldon, F. Sargeant, A. (2007) Ethical and practice issues in qualitative research. In Addington-Hall, J. (ed) *Research Methods in Palliative Care*. Oxford: Oxford University Press.
- Shilling, C. (1993) *The Body and Social Theory*. London: Sage.
- Shilling, C. Mellor, P. (1996) Embodiment, structuration theory and modernity: mind/body dualism and the repression of sensuality. *Body and Society*, 2 (4), pp.1-15.
- Shragge, J. Wismer, W. Olson, K. Baracos, V. (2006) The management of anorexia by patients with advanced cancer: a critical review of the literature. *Palliative Medicine*, 20, pp.623-629.
- Shragge, J. Wismer, W. Olson, K. Baracos, V. (2007) Shifting to conscious control: psychosocial and dietary management of anorexia by patients with advanced cancer. *Palliative Medicine*, 21, pp.227-233.
- Smart, C. Shipman, B. (2004) Visions in monochrome: families, marriage and the individualization thesis. *The British Journal of Sociology*, 55 (4), pp.491-509.
- Smart, C. (2007) *Personal Life: New Directions in Sociological Thinking*. Cambridge: Polity.
- Smith, P. (1992) *The Emotional Labour of Nursing*. London: Macmillan.

Smith, J. Braunack-Mayer, A. Wittert, G. Warin, M. (2007) I've been independent for so damn long!: Independence, masculinity and aging in a help seeking context. *Journal of Aging Studies*, 21, pp.325-335.

Smith, L.J. (2008) How ethical is ethical research? Recruiting marginalized, vulnerable groups into health services research. *Journal of Advanced Nursing*, 62 (2), pp.248-257.

Social Research Association. (2003) *Ethical Guidelines*. Scotland: Social Research Association.

Sontag, S. (1972) The double standard of aging. *Saturday Review of the Society*, 1 (1), pp.29-38.

Sontag, S. (1978) *Illness as Metaphor*. New York: McGraw-Hill.

Stalker, K. (1998) Some ethical and methodological issues in research with people with learning difficulties. *Disability and Society*, 13 (1), pp.5-19.

Stevens, M. Lord, B. Proctor, M. Nagy, S. O'Riordan, E. (2009) Research with vulnerable families caring for children with life-limiting conditions. *Qualitative Health Research*, 20, pp.496-505.

Strasser, F. Binswanger, J. Cerny, T. Kesselring, A. (2007) Fighting a losing battle: eating-related distress of men with advanced cancer and their female partners: a mixed-methods study. *Palliative Medicine*, 21, pp.129-137.

Strauss, A. Fagerhaugh, S. Suczek, B. Wiener, C. (1982) Sentimental work in the technological hospital. *Sociology of Health and Illness*, 4 (3), pp.254-278.

- Strauss A.L., Fagerhaugh S., Suczek B. Wiener C. (1982) Sentimental work in the technologized hospital. *Sociology of Health and Illness*, 4(3), pp.254–278.
- Strauss, A. Fagerhaugh, S. Suczek, B. Wiener, C. (1985) *Social Organization of Medical Work*. Chicago: University of Chicago Press.
- Strauss, A. and Corbin, J. (1991) *Basics of Qualitative Research*. London: Sage.
- Street, A.F. Kissane, D.W. (2001) Discourses of the body in euthanasia: symptomatic, dependent, shameful and temporal. *Nursing Inquiry*, 8 (3), pp.162-172.
- Sudnow, D. (1967) *Passing On: the Social Organisation of Dying*. London: Prentice-Hall International.
- Swain, J. Heyman, B. Gillman, M. (1998) Public research, private concerns: ethical issues in the use of open-ended interviews with people who have learning difficulties. *Disability and Society*, 13 (1), pp.21-36.
- Sweeting, H. Gilhooly, M. (1997) Dementia and the phenomenon of social death. *Sociology of Health and Illness*, 19 (1), pp.93-117.
- Tadd, W. (2006) Dignity and older Europeans, Cardiff Centre for Ethics, Law and Society, viewed at 19 July 2010
- <http://www.ccels.cf.ac.uk/archives/publications/2006/taddpaper.pdf>
- Taleporos, G. McCabe, M. (2002) Body image and physical disability – personal perspectives. *Social Science and Medicine*, 54, pp.971-980.
- Tavora, I. (2012) The southern European social model: familialism and the high rates of female employment in Portugal. *Journal of European Social Policy*, 22 (1), pp.63-76.

- Tee, S. Lathlean, J. (2004) The ethics of conducting a co-operative inquiry with vulnerable people. *Journal of Advanced Nursing*, 47 (5), pp.536-543.
- Terry, W. Olson, L. Ravenscroft, P. Wills, L. Boulton-Lewis, G. (2000) Hospice patient's views on research in palliative care. *Internal Medicine Journal*, 36, pp.403-413.
- Timmermans, S. (1994) Dying of awareness: the theory of awareness contexts revisited. *Sociology of Health and Illness*, 16 (3), pp.322-339.
- Timmermans, S. Sudnow, D. (1998) Social Death as Self-Fulfilling Prophecy: David Sudnow's "Passing On. *The Sociological Quarterly*, 39 (3), pp.453-472.
- Thienhaus, O. Conter, E. Bosmann, B. (1986) Sexuality and ageing. *Ageing and Society*, 6, pp.39-54.
- Thomas, C. Morris, S. Harman, J. (2002) Companions through cancer. *Social Science and Medicine*, 54 (4), pp. 529-544.
- Thomas, C. Morris, S. Clark, D. (2004) Place of death: preferences among cancer patients and their carers. *Social Science and Medicine*, 58, pp.2431–2444.
- Thomas, C. Reeve, J. Bingley, A. Blown, J. Payne, S. Lynch, T. (2009) Narrative research methods in palliative care contexts: two case studies. *Journal of Pain and Symptom Management*, 37 (5), pp.788-796.
- Thorpe, G. McArthur, M. Richardson, B. (2009) Bodily change following faecal stoma formation: qualitative interpretive synthesis. *Journal of Advanced Nursing*, 65 (9), pp.1778-1789.

- Thulesius, H. Hakansson, A. Petersson, K. (2003) Balancing: a basic process in end of life cancer care. *Qualitative Health Research*, 13 (10), pp.1353-1377.
- Toerien, M. Wilkinson, S. (2003) Gender and body hair: constructing the feminine woman. *Women's Studies International Forum*, 26 (4), pp.333-344.
- Tomassini, C. Glaser, K. Stuchbury, R. (2007) Family Disruption and Support in Later Life: A Comparative Study Between the United Kingdom and Italy. *Journal of Social Issues*, 63 (4), pp. 845—863.
- Toombs, S. (1995) The lived experience of disability. *Human Studies*, 18, pp.9-23.
- Townsend, J. Frank, A. Fermant, D. Dyer, S. Karan, O. Walgrove, A. (1990) Terminal cancer care and patients' preference for place of death: a prospective study. *British Medical Journal*, 301, pp.415-427.
- Trincão, V. (2009) *Comunicação intrafamiliar sobre o final de vida e de morte. Tese de Mestrado em Cuidados Paliativos*. Lisboa: Faculdade de Medicina de Lisboa, Universidade Técnica de Lisboa.
- Turner, V. (1969). *The ritual process: structure and anti-structure*. Chicago: Aldine Publishing Co.
- Turner, B.S. (1984) *The Body and Society*. London: Sage.
- Turner, B.S. (1987) *Medical Power and Social Knowledge*. London: Sage.
- Turner B.S. (1992) *Regulating Bodies: Essays in Medical Sociology*. London: Routledge.

- Turner B.S. (1995) Ageing and identity: some reflections on the somatisation of the self. In M. Featherstone, A. Werwick (eds) *Images of Aging: Cultural Representations on Later Life*. London: Routledge.
- Turner, B.S. Wainwright, S.P. (2003) Corps de Ballet: the case of the injured ballet dancer. *Sociology of Health and Illness*, 25 (4), pp.269-288.
- Turner, V.W. (1969) Liminality and communitas. In V.W. Turner (ed) *The Ritual Process: Structure and Anti-Structure*. Chicago: Aldine.
- Twigg, J. (1997) *Bathing and the Politics of Care*. *Social Policy & Administration*, 31 (1), pp. 61–72.
- Twigg, J. (1999) The spatial ordering of care: public and private in bathing support at home. *Sociology of Health and Illness*, 21 (4), pp.381-400.
- Twigg, J. (2000) Carework as a form of bodywork. *Ageing and Society*, 20, pp.380-411.
- Twigg, J. (2004) The body, gender, and age: Feminist insights in social gerontology. *Journal of Aging Studies*, 18, pp.59–73.
- Twigg, J. (2006) *The Body in Health and Social Care*. Palgrave Hampshire: Macmillan.
- Twigg, J. 2007. Clothing, age and the body: a critical review. *Ageing and Society*, 27, 2, 285–305.
- Twigg, J. Buse, C. (2013) Dress, dementia and the embodiment of identity, *Dementia*. 12 (3), pp.326-336.

Ussher, J. Sandoval, M. Perz, J. Wong, T. Butow, P. (2013) The Gendered Construction and Experience of Difficulties and Rewards in Cancer Care. *Qualitative Health Research*, 93, pp.900-915.

Valentine, G. (1999) Eating in: home, consumption and identity. *The Sociological Review*, 47 (3), pp.491-524.

Vale de Almeida (2004) *The Hegemonic Male Masculinity in a Portuguese Town*. Oxford: Berghahn Books.

Van Gennep, A. (1960) *The Rites of Passage*. London: Routledge and Kegan Paul.

Vilaça, H. (2012) Portugal: secularization and religious vitality of the Roman Catholic Church in a Southern European country. In Pollack, D. Muller, O. Pickel, G. (eds) *The Social Significance of Religion in the Enlarge Europe: Secularization, Individualization and Pluralization*. Surrey: Ashgate Publishing Limited.

Wainwright, S.P. Turner, B.S. (2006) Just Crumbling to Bits? An Exploration of the Body, Ageing, Injury and Career in Classical Ballet Dancers. *Sociology*, 40, pp.237-255.

Wall, K. Aboim, S. Cunha, V. and Vasconcelos, P. (2001) Families and informal support networks in Portugal: the reproduction of inequality. *Journal of European Social Policy*, 11 (3), pp.213-233.

Wall, D. Kristjanson, L. (2005) Men, culture and hegemonic masculinity: understanding the experience of prostate cancer. *Nursing Inquiry*, 12 (2), pp.87-97.

Walshe, C. Caress, A.L. Chew-Graham, C. Todd, C. (2004) Case studies: a research strategy appropriate for palliative care? *Palliative Medicine*, 18, pp.677-684.

- Walter, T. (1991) Modern death: taboo or not taboo? *Sociology*, 25 (2), pp.293-310.
- Walter, T. (1994) *The Revival of Death*, London: Routledge.
- Walters ,G. (2004) Is there such a thing as a Good Death? *Palliative Medicine*, 18, pp.404-408.
- Ward, R. Holland, C. (2011) ‘If I look old, I will be treated old’: hair and later-life image dilemmas. *Ageing and Society*, 31 (2), pp.288–307.
- Ward, R. Campbell, S. Keady, J. (2014) ‘Once I had money in my pocket, I was every colour under the sun’: Using ‘appearance biographies’ to explore the meanings of appearance for people with dementia, *Journal of Aging Studies*, 30, pp. 64–72.
- Warin, M. (2004) Primitivising Anorexia: The Irresistible Spectacle of Not Eating. *The Australian Journal of Anthropology*, 15 (1), pp.95-104.
- Watts, J. (2008) Emotion, empathy and exit: reflections on doing ethnographic qualitative research on sensitive topics. *Medical Sociology Online*, 3 (2), pp.3-14.
- West, C. Zimmerman, D. (1987) Doing gender. *Gender and Society*, 1 (2), pp.125-151.
- Whitcher, S. Fisher, J. (1979) Multidimensional reaction to therapeutic touch in a hospital setting. *Journal of Personality and Social Psychology*, 37 (1), pp.87-96.
- Whitaker, A. (2010) The body as existential midpoint –the aging and dying body of nursing home residents. *Journal of Aging Studies*, 24, pp.96-104.
- Wiersma, E. Dupuis, S. (2010) Becoming institutional bodies: socialization into a long-term care home. *Journal of Aging Studies*, 24, pp.278-291.

Widding Isaksen, L. (2002) Toward a Sociology of (Gendered) Disgust : Images of Bodily Decay and the Social Organization of Care Work. *Journal of Family Issues*, 23 (7), pp.791-811.

Wilcock, A. (2006) Anorexia: a taste of things to come?. *Palliative Medicine*, 20, pp.43-45.

Williams, S.J. Bendelow, G. (1996a) The 'Emotional' Body, *Body and Society*, 2 (3), pp.125-139.

Williams, S.J. Bendelow, G. (1998a) *The Lived Body: Sociological Themes, Embodied Issues*. London: Routledge.

Williams G.H. (1984) The genesis of chronic illness: narrative reconstruction, *Sociology of Health and Illness*, 6 (2), pp.175-200.

Williams S.J. (1996a) Medical sociology, chronic illness and the body: a rejoinder to Kelly and Field. *Sociology of Health and Illness*, 18 (5), pp.699-709.

Williams S.J. (1996b) The vicissitudes of embodiment across the chronic illness trajectory. *Body and Society*, 2 (2), pp.23-47.

Williams, S.J. Bendelow, G. (1998b) In search of the missing body: pain, suffering and the (post) modern condition. In G. Scambler, and P. Higgs, (eds). *Modernity, Medicine and Health*. London: Routledge.

Williams, S.J. Bendelow, G. (2000) Recalcitrant bodies? Children, cancer and the transgression of corporeal boundaries. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 4 (1), pp.51-71

- Williams S.J. (2000) Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health and Illness*, 22 (1), pp.40-67.
- Williams, M. (2000) Interpretivism and Generalisation. *Sociology*, 34, pp.209-224.
- Willis, E. Miller, R. Wyn, J. (2001) Gendered embodiment and survival for young people with cystic fibrosis. *Social Science and Medicine*, 53, pp.1163-1174.
- Wilkie, P. (2001) Ethical issues in qualitative research in palliative care. In Field, D. (ed) *Researching Palliative Care*. Buckingham: Open University Press.
- Wilkinson, I. (2005) *Suffering: A sociological introduction*. Cambridge: Polity Press.
- Winslow, M. Seymour, J. Clark, D. (2005) Stories of cancer pain: a historical perspective. *Journal of Pain and Symptom Management*, 29 (1), pp.22-31.
- Winslow, M. Hitchcock, K. Noble, B. (2009) Recording Lives: The benefits of an oral history service. *European Journal of Palliative Care*, 16 (3), pp.128-130.
- Winter, L. Parks, S. (2008) Family Discord and Proxy Decision Makers' End of life Treatment Decisions. *Journal of Palliative Medicine*, 11 (8), pp.1109-1114.
- Wong, O. (2005) Gender and intimate caregiving for the elderly in Hong Kong. *Journal of Ageing Studies*, 19, pp.375–391.
- Wray, N. Markovic, M. Manderson, L. (2007) Researcher saturation: impact of data triangulation and intensive-research practices on the researcher and qualitative research process. *Qualitative Health Research*, 17 (10), pp.1392-1402.

Zimmermann, C. Rodin, G. (2004) The denial of death thesis: sociological critique and implications for palliative care. *Palliative Medicine*, 18, pp.121-128.

Zimmermann, C. (2004) Denial of impending death: a discourse analysis of the palliative care literature. *Social Science and Medicine*, 59, pp.1769-1780.

Zimmermann, C. (2007) Death denial: obstacle or instrument for palliative care? An analysis of clinical literature. *Sociology of Health and Illness*, 29 (2), pp.297-314.

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Appendix 1 – Final Result of the Application to the Committee

Application no: 05/2010

ROYAL HOLLOWAY
University of London

ETHICS COMMITTEE

Final Result of Application to the Committee

Name of Applicant: Ana Patricia Hilario
Department: Health and Social Care
Title of Project: Silenced Bodies: Dying Patient's Experiences in Portugal

✓	Has been approved by the Committee
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.....
Professor Geoff Ward
Chair, Ethics Committee

..... 2/3/10
Date

Appendix 2 – Result of the Application to the Committee (Amendments List)

Application no: 05/2010 Amendment 1
July 2010

ROYAL HOLLOWAY
University of London

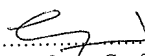
ETHICS COMMITTEE

Result of Application to the Committee

Name of Applicant: Ana Patricia Hilario
Department: Health and Social Care
Title of Project: Silenced Bodies: Dying Patient's Experiences in Portugal

This is to notify you that the amendments listed below:

	Has been approved by the Committee
✓	<p>have been approved under Chair's Action, this decision to be reported to the Committee at its next meeting</p> <ul style="list-style-type: none"> ▪ extend fieldwork to the Palliative Care Unit of Casa de Saude da Idanha, Lisbon ▪ change sample from <ul style="list-style-type: none"> - twenty (20) palliative care patients to ten (10) care palliative care patients - ten (10) relatives to twenty (20) relatives of palliative care patients - ten (10) palliative care professionals to twenty (20) palliative care professionals ▪ seek formal consent from relatives when the patient is unable to give formal consent due to physical deterioration or cognitive impairment ▪ change the minimum age of patients to be observed and interviewed, from thirty to eighteen years.

.....

Professor Geoff Ward
Chair, Ethics Committee
..... 24 / 8 / 10Date

Appendix 3 – Consent Form D (English)

The body and its shadows: an exploration of the bodily experiences of palliative care patients

Observation Consent Form for Observe Palliative Care Patients

This consent form outlines your rights as a participant in the study of the experiences of palliative care patients conducted by Ana Patricia Hilario from the Centre for Criminology and Sociology, Royal Holloway, University of London, UK. The research is supported by the Centre for Research Studies in Sociology, Lisbon University Institute, Portugal, and is funded by the Portuguese Foundation of Science and Technology.

1. I have read (or Ana Patricia has read to me) and understand the information [] sheet provided by the research student.
2. I have been able to ask questions about the nature and purposes of the research [] and they have been answered satisfactorily.
3. I agree to be observed for the purposes of the study specified above and I [] agree that the observation will be recorded in the fieldwork diary.
4. I have been informed that participation is voluntary and that I can withdraw at [] any time without giving a reason and that my care in the palliative care unit will not be affected in any way.
5. I have been assured that my right to anonymity, privacy and confidentiality [] will be preserved.
6. I have been informed that my identity will be disclosure if I wish like. []
 - 6.1. I want to remain anonymous through the use of a pseudonym. []
 - 6.2. I do not want to be anonymous, thus my name can be used. []

Name of respondent: _____

Signature of respondent: _____

7. I have explained the above study and the implications of being observed to [] the participant and I believe that s(he) understands all the implications of participation.

Name of researcher: _____

Signature of researcher: _____

Date: _____

Appendix 4 – Consent Form E (English)

The body and its shadows: an exploration of the bodily experiences of palliative care patients

Observation Consent Form for Observe Palliative Care Patients and their Family Members

This consent form outlines your rights as a participant in the study of the experiences of palliative care patients conducted by Ana Patricia Hilario from the Centre for Criminology and Sociology, Royal Holloway, University of London, UK. The research is supported by the Centre for Research Studies in Sociology, Lisbon University Institute, Portugal, and is funded by the Portuguese Foundation of Science and Technology.

1. I have read (or Ana Patricia has read to me) and understand the information [] sheet provided by the research student.
2. I have been able to ask questions about the nature and purposes of the research [] and they have been answered satisfactorily.
3. I agree to be observed for the purposes of the study specified above and I [] agree that the observation will be recorded in the fieldwork diary.
4. I have been informed that participation is voluntary and that I can withdraw at [] any time without giving a reason and that my care in the palliative care unit will not be affected in any way.
5. I have been assured that my right to anonymity, privacy and confidentiality [] will be preserved.
6. I have been informed that my identity will be disclosure if I wish like. []
 - 6.1. I want to remain anonymous through the use of a pseudonym. []
 - 6.2. I do not want to be anonymous, thus my name can be used. []

Name of respondent: _____

Signature of respondent: _____

7. I have explained the above study and the implications of being observed to [] the participant and I believe that s(he) understands all the implications of participation.

Name of researcher: _____

Signature of researcher: _____

Date: _____

Appendix 5 - Research Information Sheet D (English)

The body and its shadows: an exploration of the bodily experiences of palliative care patients

Observation Research Information Sheet For Palliative Care Patients

You are being invited to take part in a study undertaken by myself, Ana Patricia Hilario, PhD research student. Before you decide it is important that you understand why the research study is being done and what it will involve. Please take time to read this information sheet. If you would like to have more information or if anything is not clear, please ask me. I am here to help you.

Who is organising and funding the research study?

This research study is being conducted by Ana Patricia Hilario, a PhD student in the Centre of Criminology and Sociology, Royal Holloway, University of London, Egham, United Kingdom. The research is supported by the Centre for Research Studies in Sociology, Lisbon University Institute, Lisbon, Portugal, and is funded by the Portuguese Foundation of Science and Technology.

What is the purpose of the research study?

The aim of this research study is to understand the experiences of palliative care patients and those who care for them. I am particularly interested to understand your experience of living with an illness, thus attention will be paid to the ways in which the illness affects your daily living and your interaction with others. I am interested in getting your daily experience of such topics as: your care, your capacity to control your body, your appearance, your sense of self and sense of dignity. This study might help to improve the palliative care given to future patients.

What will happen to me if I take part on the research study?

If you decide to take part on the study you will be asked to read and sign a consent form. The research student will then observe your daily routine. The observation is expected to last at maximum five months and will be recorded in a fieldwork diary so that I can remember what has happened. During the observation I may write some notes down so that I do not forget any important issue. Your name will never be used so no one will be able to identify you, unless you want to. Your right of privacy, confidentiality and anonymity will be respected. Your signed consent form will be stored separately from the responses you provide.

What are the possible disadvantages and risks of taking part on the research study?

The experience of living with an illness might emotionally upset you. If this happens you will be asked if you want to stop the observation and a psychologist from the palliative care unit will be available for an appointment if you need this. If you decide to stop the observation and withdraw for the study this will not affect your care in the palliative care in any way.

What will happen to the results of the research study?

The information collected by the researcher will only be used for research purposes and will be treated in confidence by the research student and her supervisor Professor Jonathan Gabe. The results of the research study will be published in a PhD thesis as well as in articles in academic journals. The research student will also talk about the results in academic conferences. A report of the study will be given to you and/or to your relatives. You will never be identified in any presentation, publication or report, unless you want to.

How can I contact for further information?

If you have any questions about the study, please contact the PhD research student:

Name: Ana Patricia Hilario

Address: CIES-ISCTE | Edifício ISCTE, Av. das Forças Armadas | 1649-026 Lisboa

Telephone: (00351) 968 380 121

Email: patriciahilario@gmail.com

You can also contact the Supervisor of the PhD research student

Name: Jonathan Gabe

Address: Royal Holloway, University of London, Egham Hill, Egham, Surrey, TW20 0EX

Telephone: (0044) 178 444 314 4

Email: J.Gabe@rhul.ac.uk

Thank you for taking the time to read this form.

You may retain this form for reference.

Appendix 6 - Research Information Sheet E (English)

The body and its shadows: an exploration of the bodily experiences of palliative care patients

Observation Research Information Sheet For Palliative Care Patients and their Family Members

You are being invited to take part in a study undertaken by myself, Ana Patricia Hilario, PhD research student. Before you decide it is important that you understand why the research study is being done and what it will involve. Please take time to read this information sheet. If you would like to have more information or if anything is not clear, please ask me. I am here to help you.

Who is organising and funding the research study?

This research study is being conducted by Ana Patricia Hilario, a PhD student in the Centre of Criminology and Sociology, Royal Holloway, University of London, Egham, United Kingdom. The research is supported by the Centre for Research Studies in Sociology, Lisbon University Institute, Lisbon, Portugal, and is funded by the Portuguese Foundation of Science and Technology.

What is the purpose of the research study?

The aim of this research study is to understand the experiences of palliative care patients and those who care for them. I am particularly interested to understand your relative experience of living with an illness, thus attention will be paid to the ways in which the illness affects the daily living of your relative and his/her interaction with others. I am interested in getting the daily experience of such topics as: the care experience of your relative, his/her capacity to control the body, his/her appearance, his/her sense of self and sense of dignity. This study might help to improve the palliative care given to future patients.

What will happen to me if I take part on the research study?

If you decide to take part on the study you will be asked to read and sign a consent form. The research student will then observe the daily routine of your relative. The observation is expected to last at maximum five months and will be recorded in a fieldwork diary so that I can remember what has happened. During the observation I may write some notes down so that I do not forget any important issue. Your name will never be used so no one will be able to identify you. Your right of privacy, confidentiality and anonymity will be respected. Your signed consent form will be stored separately from the responses you provide.

What are the possible disadvantages and risks of taking part on the research study?

The experience of your relative living with an illness might emotionally upset you. If this happens you will be asked if you want to stop the observation and a psychologist from the palliative care unit will be available for an appointment if you need this. If you decide to stop the observation and withdraw from the study this will not affect the care of your relative in the palliative care in any way.

What will happen to the results of the research study?

The information collected by the researcher will only be used for research purposes and will be treated in confidence by the research student and her supervisor Professor Jonathan Gabe. The results of the research study will be published in a PhD thesis as well as in articles in academic journals. The research student will also talk about the results in academic conferences. A report of the study will be given to you. You will never be identified in any presentation, publication or report, unless you want to.

How can I contact for further information?

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Telephone: (00351) 968 380 121

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You can also contact the Supervisor of the PhD research student

Name: Jonathan Gabe

Address: Royal Holloway, University of London, Egham Hill, Egham, Surrey, TW20 0EX

Telephone: (0044) 178 444 314 4

Email: J.Gabe@rhul.ac.uk

**Thank you for taking the time to read this form.
You may retain this form for reference.**

Appendix 7 - Research Information Sheet A (English)

The body and its shadows: an exploration of the bodily experiences of palliative care patients

Interview Research Information Sheet For Palliative Care Patients

You are being invited to take part in a research study undertaken by myself, Ana Patricia Hilario, PhD research student. Before you decided it is important that you understand why the research study is being done and what it will involve. Please take time to read this information sheet. If you would like to have more information or if anything is not clear, please ask me. I am here to help you.

Who is organising and funding the research study?

This study is being conducted by Ana Patricia Hilario, a PhD student from the Centre of Criminology and Sociology, Royal Holloway, University of London, Egham, United Kingdom. The research is supported by the Centre for Research Studies in Sociology, Lisbon University Institute, Lisbon, Portugal, and is funded by the Portuguese Foundation of Science and Technology.

What is the purpose of the research study?

The aim of this study is to understand the experiences of palliative care patients and those who care for them. I am particularly interested to understand how you feel about having an illness. I am interested in getting your opinion about the experience of living with this illness; thus attention will be paid to the ways in which the illness affects your daily living and your involvement with others. I intend to explore your opinion about such topics as: your illness experience, your care, your capacity to control your body, your appearance, your sense of self and sense of dignity. This study might help to improve the palliative care given to future patients.

What will happen to me if I take part on the research study?

If you decide to take part in this study you will be asked to read and sign a consent form. You will be invited to speak with the research student about some of the things mentioned above. The interview is expected to last around 60 to 90 minutes and will be tape-recorded so that I can remember what you have said. During the interview I might make some notes so that I do not forget to ask you any important issue. After I had transcribed the interview the tapes will be destroyed. Your name will never be used so no one will be able to identify you, unless you want to. Your right of privacy, confidentiality and anonymity will be respected. Your signed consent form will be stored separately from the responses you provide.

What are the possible disadvantages and risks of taking part on the research study?

Talking about the experience of living with an illness might emotionally upset you. If this happens you will be asked if you want to stop the interview and a psychologist from the palliative care unit will be available for an appointment if you need this. If you decide to stop the interview and withdraw from the study this will not affect your care in the palliative care unit in any way.

What will happen to the results of the research study?

The information given in the interview will only be used for research purposes and will be treated in confidence by the research student and her supervisor Professor Jonathan Gabe. The results of the research will be published in a PhD thesis as well as in articles in academic journals. The research student will also talk about the results at academic conferences. A report of the study will be given to you and/or to your relatives. You will never be identified in any presentation, publication or report, unless you want to.

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Telephone: (0044) 178 444 314 4

Email: J.Gabe@rhul.ac.uk

Thank you for taking the time to read this form.

You may retain this form for reference.

Appendix 8 – Research Information Sheet B (English)

The body and its shadows: an exploration of the bodily experiences of palliative care patients

Interview Research Information Sheet For Patients' Relatives

You are being invited to take part in a study undertaken by myself, Ana Patricia Hilario, PhD research student. Before you decide it is important that you understand why the research is being done and what it will involve. Please take time to read this information sheet. If you would like to have more information or if anything is not clear, please ask me. I am here to help you.

Who is organising and funding the research study?

This study is being conducted by Ana Patricia Hilario, a PhD student from the Centre of Criminology and Sociology, Royal Holloway, University of London, Egham, United Kingdom. The research is supported by the Centre for Research Studies in Sociology, Lisbon University Institute, Lisbon, Portugal, and is funded by the Portuguese Foundation of Science and Technology.

What is the purpose of the research study?

The aim of this study is to understand the experiences of palliative care patients and those who care for them. I am particularly concerned to understand your opinion about several aspects of the illness of your relative, in other words how your relative feels to have an illness. I am interested in getting your opinion about the experience of your relative of living with an illness thus attention will be paid to the ways in which the illness affects the daily living of your relative and his/her involvement with others. I intend to explore your opinion about such topics as: the illness experience of your relative, their ability to control their body, their appearance, their sense of self and their sense of dignity. This study might help to improve the palliative care given to future patients.

What will happen to me if I take part on the research study?

If you decide to take part on the study you will be asked to read and sign a consent form. You will be invited to speak with the research student about some of the topics considered above. The interview is expected to last around 60 to 90 minutes and will be tape-recorded so that I can remember what you have said. During the interview I might write some notes down so that I do not forget to ask you about any important issue. After I had transcribed the interview the tapes will be destroyed. Your name will never be used so no one will be able to identify you, unless you want to. Your right of privacy,

confidentiality and anonymity will be respected. Your signed consent form will be stored separately from the responses you provide.

What are the possible disadvantages and risks of taking part on the research study?

Talking about the experience of your relative living with an illness might emotionally upset you. If this happens you will be asked if you want to stop the interview and a psychologist from palliative care unit will be available for an appointment if you need this. If you decide to stop the interview and withdraw from the study this will not affect the care of your relative in the palliative care unit in any way.

What will happen to the results of the research study?

The information given in the interview will only be used for research purposes and will be treated in confidence by the research student and her supervisor Professor Jonathan Gabe. The results of the research study will be published in a PhD thesis as well as in articles in academic journals. The research student will also talk about the results in academic conferences. A report of the study will be given to you. You will never be identified in any presentation, publication or report, unless you want to.

How can I contact for further information?

If you have any questions about the study, please contact the PhD research student:

Name: Ana Patricia Hilario

Address: CIES-ISCTE, Edifício ISCTE, Av. das Forças Armadas, 1649-026 Lisboa

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You can also contact the Supervisor of the PhD research student

Name: Jonathan Gabe

Address: Royal Holloway, University of London, Egham Hill, Egham, Surrey, TW20 0EX

Telephone: (0044) 178 444 314 4

Email: J.Gabe@rhul.ac.uk

**Thank you for taking the time to read this form.
You may retain this form for reference.**

Appendix 9 – Research Information Sheet C (English)

The body and its shadows: an exploration of the bodily experiences of palliative care patients

Interview Research Information Sheet For Palliative Care Professionals

You are being invited to take part in a study undertaken by myself, Ana Patricia Hilario, PhD research student. Before you decide it is important that you understand why the research is being done and what it will involve. Please take time to read this information sheet. If you would like to have more information or if anything is not clear, please ask me. I am here to help you.

Who is organising and funding the research study?

This research study is being conducted by Ana Patricia Hilario, a PhD student at the Centre of Criminology and Sociology, Royal Holloway, University of London, Egham, United Kingdom. The research is supported by the Centre for Research Studies in Sociology, Lisbon University Institute, Lisbon, Portugal, and is funded by the Portuguese Foundation of Science and Technology.

What is the purpose of the research study?

The aim of this study is to understand the experiences of palliative care patients and those who care for them. I am particularly concerned to understand your opinion about several aspects of the disease and the dying process, in other words how patients feel to have a terminal illness. I am interested in getting your opinion about the experience of palliative care patients' of living with a terminal illness thus attention will be paid to the ways in which the illness affects the daily living of palliative care patients and their interaction with others I intend to explore your opinion about such topics as: the care of terminally ill patients, their ability to control their body, their appearance, their sense of self and their sense of dignity. This study might help to improve the palliative care given to future patients.

What will happen to me if I take part on the research study?

If you decide to take part on the study you will be asked to read and sign a consent form. You will be invited to speak with the research student about some of the topics considered above. The interview is expected to last around 60 to 90 minutes and will be tape-recorded so I that I can remember what you have said. During the interview I might write some notes down so that I do not forget to ask you about any important issue. After I had transcribed the interview the tapes will be destroyed. Your name will never be used so no one will be able to identify you, unless you want to. Your right of privacy,

confidentiality and anonymity will be respected. Your signed consent form will be stored separately from the responses you provide.

What are the possible disadvantages and risks of taking part on the research study?

Talking about the experience of patients' living with a terminal illness might emotionally upset you. If this happens you will be asked if you want to stop the interview and a psychologist from the palliative care unit will be available for an appointment if you need this. If you decide to stop the interview and withdraw from the study this will not affect your work in the palliative care unit in any way.

What will happen to the results of the research study?

The information given in the interview will only be used for research purposes and will be treated in confidence by the research student and her supervisor Professor Jonathan Gabe. The results of the research study will be published in a PhD thesis as well as in articles in academic journals. The research student will also talk about the results in academic conferences. A report of the study will be given to you. You will never be identified in any presentation, publication or report, unless you want to.

How can I contact for further information?

If you have any questions about the study, please contact the PhD research student:

Name: Ana Patricia Hilario

Address: CIES-ISCTE, Edifício ISCTE, Av. das Forças Armadas, 1649-026 Lisboa

Telephone: (00351) 968 380 121

Email: patriciahilario@gmail.com

You can also contact the Supervisor of the PhD research student

Name: Jonathan Gabe

Address: Royal Holloway, University of London, Egham Hill, Egham, Surrey, TW20 0EX

Telephone: (0044) 178 444 314 4

Email: J.Gabe@rhul.ac.uk

**Thank you for taking the time to read this form.
You may retain this form for reference.**

Appendix 10 - Consent Form A (English)

The body and its shadows: an exploration of the bodily experiences of palliative care patients

Interview Consent Form for Interview Palliative Care Patients

This consent form outlines your rights as a participant in the study of the experiences of palliative care patients conducted by Ana Patricia Hilario from the Centre for Criminology and Sociology, Royal Holloway, University of London, UK. The research is supported by the Centre for Research Studies in Sociology, Lisbon University Institute, Portugal, and is funded by the Portuguese Foundation of Science and Technology.

1. I have read (or Ana Patricia has read to me) and understand the information [] sheet provided by the research student.
2. I have been able to ask questions about the nature and purpose of the research [] and they have been answered satisfactorily.
3. I agree to be interviewed for the purpose of the study specified above and I [] agree that the interview will be taped recorded and transcribed.
4. I have been informed that participation is voluntary and that I can withdraw at [] any time without giving a reason and that my care in the palliative care unit will not be affected in any way. []
5. I have been assured that my right to anonymity, privacy and confidentiality will be preserved.
6. I have been informed that my identity will be disclosure if I wish like. []
 - 6.1. I want to remain anonymous through the use of a pseudonym. []
 - 6.2. I do not want to be anonymous, thus my name can be used. []

Name of respondent: _____

Signature of respondent: _____

7. I have explained the above study and the implications of being interviewed to the respondent and I believe that s(he) understands all the implications of participation. []

Name of researcher: _____

Signature of researcher: _____

Date: _____

Appendix 11 – Consent Form B (English)

The body and its shadows: an exploration of the bodily experiences of palliative care patients

Interview Consent Form for Interview Patients' Relatives

This consent form outlines your rights as a participant in the study of the experiences of palliative care patients conducted by Ana Patricia Hilario from the Centre for Criminology and Sociology, Royal Holloway, University of London, UK. The research is supported by the Centre for Research Studies in Sociology, Lisbon University Institute, Portugal, and is funded by the Portuguese Foundation of Science and Technology.

1. I have read (or Ana Patricia has read to me) and understand the information [] sheet provided by the research student.

2. I have been able to ask questions about the nature and purposes of the research [] and they have been answered satisfactorily.

3. I agree to be interviewed for the purposes of the study specified above and I [] agree that the interview will be taped recorded and transcribed.

4. I have been informed that participation is voluntary and that I can withdraw at any time without giving a reason and that the care of my relative in the palliative [] unit will not be affected in any way.

5. I have been assured that my right to anonymity, privacy and confidentiality will [] be preserved.

6. I have been informed that my identity may be disclosed if I would like. []

6.1. I want to remain anonymous through the use of a pseudonym. []

6.2. I do not want to be anonymous, thus my name can be used. []

Name of respondent: _____

Signature of respondent: _____

7. I have explained the above study and the implications of being interviewed to the respondent and I believe that s(he) understands all the implications of participation. []

Name of researcher: _____

Signature of researcher: _____

Date: _____

Appendix 12 – Consent Form C (English)

The body and its shadows: an exploration of the bodily experiences of palliative care patients

Interview Consent Form for Interview Palliative Care Professionals

This consent form outlines your rights as a participant in the study of the experiences of palliative care patients conducted by Ana Patricia Hilario from the Centre for Criminology and Sociology, Royal Holloway, University of London, UK. The research is supported by the Centre for Research Studies in Sociology, Lisbon University Institute, Portugal, and is funded by the Portuguese Foundation of Science and Technology.

1. I have read (or Ana Patricia has read to me) and understand the information [] sheet provided by the research student.
2. I have been able to ask questions about the nature and purposes of the research [] and they have been answered satisfactorily.
3. I agree to be interviewed for the purposes of the study specified above and I [] agree that the interview will be taped recorded and transcribed.
4. I have been informed that participation is voluntary and that I can withdraw at [] any time without giving a reason and that my work role in the palliative care unit will not be affected in any way.
5. I have been assured that my right to anonymity, privacy and confidentiality will [] be preserved.
6. I have been informed that my identity will be disclosure if I wish like. []
 - 6.1. I want to remain anonymous through the use of a pseudonym. []
 - 6.2. I do not want to be anonymous, thus my name can be used. []

Name of respondent: _____

Signature of respondent: _____

7. I have explained the above study and the implications of being interviewed to [] the respondent and I believe that s(he) understands all the implications of participation.

Name of researcher: _____

Signature of researcher: _____

Date: _____

Appendix 13 - Research Information Sheet A (Portuguese)

O corpo e as suas sombras: Um olhar sobre as experiências corporais dos doentes em cuidados paliativos

Folheto Informativo sobre Entrevistas A Doentes em Cuidados Paliativos

Está a ser convidado para participar num estudo acerca das experiências dos doentes num serviço de cuidados paliativos. Antes de decidir é importante que compreenda as razões que levam à realização desta estudo e o que este envolve. Por favor leve o tempo que precisar para ler esta folha informativa. Se quiser obter mais informações ou se considerar que alguma informação não está suficientemente clara por favor pergunte-me. Estou aqui para ajudá-lo.

Quem organiza e financia este estudo?

Este estudo está a ser conduzido por Ana Patrícia Hilário, estudante de Doutoramento, no Departamento de Sociologia, da Royal Holloway-University of London, Egham, Reino Unido. Este estudo tem o apoio do Centro de Investigação e Estudos de Sociologia, do Instituto Superior de Ciências do Trabalho e da Empresa, Lisboa, Portugal. E é financiado pela Fundação para a Ciência e Tecnologia.

Qual é o objectivo deste estudo?

O objectivo do presente estudo é de contribuir para o conhecimento sobre as experiências dos doentes paliativos e dos seus cuidadores. A estudante de doutoramento está interessada em conhecer o seu ponto de vista sobre diversos aspectos da doença que o afecta. O presente estudo pretende explorar a sua opinião sobre certos temas tais como: a sua experiência da doença, os seus cuidados, a sua autonomia física e a sua capacidade de controlo corporal, a sua imagem corporal, a sua identidade e o sentido de dignidade. Este estudo irá ajudar a melhorar os cuidados dados a futuros doentes.

O que acontecerá se decidir fazer parte deste estudo?

Se decidir participar neste estudo ser-lhe-á pedido para ler e a assinar uma declaração de consentimento. Irá também ser convidado a falar sobre os tópicos acima mencionados. É esperado que a entrevista dure cerca de 60 a 90 minutos. A entrevista será gravada em formato áudio. Durante a entrevista a estudante de doutoramento poderá ler e tomar algumas notas de modo a não se esquecer de abordar todos os aspectos relacionados com o estudo. De mencionar que após a entrevista ser transcrita a gravação áudio será destruída. O seu nome nunca será usado pelo que nunca ninguém o poderá identificar. Caso deseje ser identificado e deste modo manter a sua identidade, poderá fazê-lo. O seu direito ao anonimato, privacidade e confidencialidade será sempre respeitado. A declaração de consentimento será guardada separadamente das suas respostas.

Quais são as possíveis desvantagens e riscos de tomar parte neste estudo?

Falar sobre a experiência de viver com uma doença crónica poderá aborrece-lo ou deixá-lo triste. Se isto acontecer a estudante de doutoramento irá lhe perguntar se gostaria de parar a entrevista e caso necessite a psicóloga da unidade de cuidados paliativos estará disponível para falar consigo. Se decidir parar a entrevista e desistir do estudo tal não afectará os seus cuidados na unidade de cuidados paliativos de nenhuma forma.

O que acontecerá aos resultados do estudo?

A informação dada na entrevista irá ser usada apenas no estudo e será tratada confidencialmente pela estudante de doutoramento e pelo seu supervisor o Professor Jonathan Gabe. Os resultados do estudo serão publicados na tese de doutoramento da estudante, bem como em artigos em jornais académicos. A estudante de doutoramento irá também apresentar os resultados do estudo em conferências académicas e não académicas. Um relatório será dado a si e aos seus familiares. Nunca será identificado em apresentações, publicações e relatórios, a menos que deseje manter a sua identidade.

Como e quem posso contactar em caso de dúvida?

Se tiver alguma dúvida acerca do estudo, por favor contacte a estudante de doutoramento:

Nome: Ana Patrícia Hilário

Morada: CIES-ISCTE, Edifício ISCTE, Av. das Forças Armadas, 1649-026 Lisboa

Telefone: (00351) 968 380 121

Email: patriciahilario@gmail.com

Poderá também contactar o supervisor da estudante de doutoramento:

Nome: Jonathan Gabe

Morada: Royal Holloway, University of London, Egham Hill, Egham, Surrey, TW20 0EX

Telephone: (0044) 178 444 314 4

Email: J.Gabe@rhul.ac.uk

Muito obrigada pelo tempo dispensado.

Poderá guardar este folheto informativo para referência.

Appendix 14 - Research Information Sheet B (Portuguese)

O corpo e as suas sombras: Um olhar sobre as experiências corporais dos doentes em cuidados paliativos

Folheto Informativo sobre as Entrevistas Aos Familiares dos Doentes em Cuidados Paliativos

Está a ser convidado para participar num estudo acerca das experiências dos doentes num serviço de cuidados paliativos. Antes de decidir é importante que compreenda as razões que levam à realização deste estudo e o que este envolve. Por favor leve o tempo que precisar para ler esta folha informativa. Se quiser obter mais informações ou se considerar que alguma informação não está suficientemente clara por favor pergunte-me. Estou aqui para ajudá-lo.

Quem organiza e financia este estudo?

Este estudo está a ser conduzida por Ana Patrícia Hilário, estudante de Doutoramento, no Departamento de Sociologia, da Royal Holloway-University of London, Egham, Reino Unido. Este estudo tem o apoio do Centro de Investigação e Estudos de Sociologia, do Instituto Superior de Ciências do Trabalho e da Empresa, Lisboa, Portugal. E é financiado pela Fundação para a Ciência e Tecnologia.

Qual é o objectivo deste estudo?

O objectivo do presente estudo é de contribuir para o conhecimento sobre as experiências dos doentes paliativos e dos seus cuidadores. A estudante de doutoramento está interessada em conhecer o seu ponto de vista sobre diversos aspectos da doença do seu familiar. O presente estudo pretende explorar a sua opinião sobre certos temas tais como: a experiência de doença do seu familiar, a autonomia física e a capacidade de controlo corporal do seu familiar, a imagem corporal do seu familiar, a imagem pessoal e social do seu familiar e a dignidade do seu familiar. Este estudo irá ajudar a melhorar os cuidados dados a futuros doentes.

O que acontecerá se decidir fazer parte do estudo?

Se decidir participar neste estudo ser-lhe-á pedido para ler e a assinar uma declaração de consentimento. Irá também ser convidado a falar sobre os tópicos acima mencionados. É esperado que a entrevista dure cerca de 60 a 90 minutos. A entrevista será gravada em formato áudio. Durante a entrevista a estudante de doutoramento poderá ler e tomar algumas notas de modo a não se esquecer de abordar todos os aspectos relacionados com o estudo. De mencionar que após a entrevista ser transcrita a gravação será destruída. O seu nome nunca será usado pelo que nunca ninguém o poderá identificar. Caso deseje ser identificado e deste modo manter a sua identidade, poderá fazê-lo. O seu direito ao anonimato, privacidade e confidencialidade será sempre respeitado. A declaração de consentimento será guardada separadamente das suas respostas.

Quais são as possíveis desvantagens e riscos de tomar parte neste estudo?

Falar sobre a experiência do seu familiar de viver com uma doença crónica poderá aborrece-lo ou deixá-lo triste. Se isto acontecer será lhe perguntado se gostaria de parar a entrevista e caso necessite a psicóloga da unidade de cuidados paliativos estará disponível para falar consigo. Se decidir parar a entrevista e desistir do estudo tal não afectará os cuidados do seu familiar na unidade de cuidados paliativos de nenhuma forma.

O que acontecerá aos resultados do estudo?

A informação dada na entrevista irá ser usada apenas no estudo e será tratada confidencialmente pela estudante de doutoramento e pelo seu supervisor o Professor Jonathan Gabe. Os resultados do estudo serão publicados na tese de doutoramento da estudante, bem como em artigos em jornais académicos. A estudante de doutoramento irá também apresentar os resultados do estudo em conferências académicas e não académicas. Um relatório será dado a si. Nunca será identificado em apresentações, publicações e relatórios, a menos que deseje manter a sua identidade.

Como e quem posso contactar em caso de dúvida?

Se tiver alguma dúvida acerca do estudo, por favor contacte a estudante de doutoramento:

Nome: Ana Patrícia Hilário

Morada: CIES-ISCTE, Edifício ISCTE, Av. das Forças Armadas, 1649-026 Lisboa

Telefone: (00351) 968 380 121

Email: patriciahilario@gmail.com

Poderá também contactar o supervisor da estudante de doutoramento:

Nome: Jonathan Gabe

Morada: Royal Holloway, University of London, Egham Hill, Egham, Surrey, TW20 0EX

Telephone: (0044) 178 444 314 4

Email: J.Gabe@rhul.ac.uk

Muito obrigada pelo tempo dispensado.

Poderá guardar este folheto informativo para referência.

Appendix 15 - Research Information Sheet C (Portuguese)

O corpo e as suas sombras: Um olhar sobre as experiências corporais dos doentes em cuidados paliativos

Folheto Informativo sobre as Entrevistas Aos Profissionais de Cuidados Paliativos

Está a ser convidado para participar num estudo acerca das experiências dos doentes num serviço de cuidados paliativos. Antes de decidir é importante que compreenda as razões que levam à realização deste estudo e o que este envolve. Por favor leve o tempo que precisar para ler esta folha informativa. Se quiser obter mais informações ou se considerar que alguma informação não está suficientemente clara por favor pergunte-me. Estou aqui para ajudá-lo.

Quem organiza e financia este estudo?

Este estudo está a ser conduzido por Ana Patrícia Hilário, estudante de Doutoramento, no Departamento de Sociologia, da Royal Holloway-University of London, Egham, Reino Unido. Este estudo tem o apoio do Centro de Investigação e Estudos de Sociologia, do Instituto Superior de Ciências do Trabalho e da Empresa, Lisboa, Portugal. E é financiado pela Fundação para a Ciência e Tecnologia.

Qual é o objectivo desta estudo?

O objectivo da presente estudo é de contribuir para o conhecimento sobre as experiências dos doentes paliativos e dos seus cuidadores. A estudante de doutoramento está interessada em conhecer o seu ponto de vista sobre diversos aspectos da doença terminal e dos cuidados prestados aos doentes em cuidados paliativos. Este estudo pretende explorar a sua opinião sobre certos temas tais como: os cuidados prestados aos doentes terminais, a autonomia física e a capacidade de controlo corporal dos doentes terminais, a imagem corporal dos doentes terminais, a identidade pessoal e social dos doentes terminais e o sentido de dignidade dos doentes terminais. Este estudo irá ajudar a melhorar os cuidados dados a futuros doentes

O que acontecerá se decidir fazer parte do estudo?

Se decidir participar neste estudo ser-lhe-á pedido para ler e a assinar uma declaração de consentimento. Irá também ser convidado a falar sobre os tópicos acima mencionados. É esperado que a entrevista dure cerca de 60 a 90 minutos. A entrevista será gravada em formato áudio. Durante a entrevista a estudante de doutoramento poderá ler e tomar algumas notas de modo a não se esquecer de abordar todos os aspectos relacionados com o estudo. De mencionar que após a entrevista ser transcrita a gravação áudio será destruída. O seu nome nunca será usado pelo que nunca ninguém o poderá identificar. Caso deseje ser identificado e deste modo manter a sua identidade, poderá fazê-lo. O seu direito ao anonimato, privacidade e confidencialidade será sempre respeitado. A declaração de consentimento será guardada separadamente das suas respostas.

Quais são as possíveis desvantagens e riscos de tomar parte neste estudo?

Falar sobre a experiência dos doentes em fase terminal poderá aborrece-lo ou deixá-lo triste. Se isto acontecer será lhe perguntado se gostaria de parar a entrevista e caso necessite a psicóloga da unidade de cuidados paliativos estará disponível para falar consigo. Se decidir parar a entrevista e desistir do estudo tal não afectará o seu trabalho na unidade de cuidados paliativos de nenhuma forma.

O que acontecerá aos resultados do estudo?

A informação dada na entrevista irá ser usada apenas no estudo e será tratada confidencialmente pela estudante de doutoramento e pelo seu supervisor o Professor Jonathan Gabe. Os resultados do estudo serão publicados na tese de doutoramento da estudante, bem como em artigos em jornais académicos. A estudante de doutoramento irá também apresentar os resultados do estudo em conferências académicas e não académicas. Um relatório será dado a si e aos restantes profissionais que participaram no estudo. Nunca será identificado em apresentações, publicações e relatórios, a menos que deseje manter a sua identidade.

Como e quem posso contactar em caso de dúvida?

Se tiver alguma dúvida acerca do estudo, por favor contacte a estudante de doutoramento:

Nome: Ana Patrícia Hilário

Morada: CIES-ISCTE, Edifício ISCTE, Av. das Forças Armadas, 1649-026 Lisboa

Telefone: (00351) 968 380 121

Email: patriciahilario@gmail.com

Poderá também contactar o supervisor da estudante de doutoramento:

Nome: Jonathan Gabe

Morada: Royal Holloway, University of London, Egham Hill, Egham, Surrey, TW20 0EX

Telephone: (0044) 178 444 314 4

Email: J.Gabe@rhul.ac.uk

Muito obrigada pelo tempo dispensado.

Poderá guardar este folheto informativo para referência.

Appendix 16 - Research Information Sheet D (Portuguese)

O corpo e as suas sombras: Um olhar sobre as experiências corporais dos doentes em cuidados paliativos

Folheto Informativo sobre a Observação Dos Doentes em Cuidados Paliativos

Está a ser convidado para participar num estudo acerca das experiências dos doentes num serviço de cuidados paliativos. Antes de decidir é importante que compreenda as razões que levam à realização deste estudo e o que este envolve. Por favor leve o tempo que precisar para ler esta folha informativa. Se quiser obter mais informações ou se considerar que alguma informação não está suficientemente clara por favor pergunte-me. Estou aqui para ajudá-lo.

Quem organiza e financia este estudo?

Este estudo está a ser conduzido por Ana Patrícia Hilário, estudante de Doutoramento, no Departamento de Sociologia, da Royal Holloway-University of London, Egham, Reino Unido. Este estudo tem o apoio do Centro de Investigação e Estudos de Sociologia, do Instituto Superior de Ciências do Trabalho e da Empresa, Lisboa, Portugal. E é financiado pela Fundação para a Ciência e Tecnologia.

Qual é o objectivo deste estudo?

O objectivo do presente estudo é de contribuir para o conhecimento sobre as experiências dos doentes paliativos e dos seus cuidadores. A estudante de doutoramento está interessada em compreender a sua experiência de viver com uma doença e por conseguinte será dada atenção ao modo como a doença afecta a sua rotina diária e a sua interacção com os outros. Este estudo pretende explorar a sua experiência quotidiana pelo que irá incidir sobre certos temas tais como: os cuidados que lhe são prestados, a sua autonomia física e a sua capacidade de controlo corporal, a sua imagem corporal, a sua identidade pessoal e social e o seu sentido de dignidade. Este estudo irá ajudar a melhorar os cuidados dados a futuros doentes.

O que acontecerá se decidir fazer parte do estudo?

Se decidir participar neste estudo ser-lhe-á pedido para ler e a assinar uma declaração de consentimento. Após ter obtido o seu consentimento a estudante de doutoramento irá observar as suas rotinas diárias. A informação recolhida será guardada num diário de campo de modo a que a estudante de doutoramento consiga recordar o que aconteceu. Durante a observação a estudante de doutoramento poderá tirar algumas notas de forma a não se esquecer de algum aspecto importante. O seu nome nunca será usado pelo que nunca ninguém o poderá identificar. Caso deseje ser identificado e deste modo manter a sua identidade, poderá fazê-lo. O seu direito ao anonimato, privacidade e confidencialidade será sempre respeitado. A declaração de consentimento será guardada separadamente das suas respostas.

Quais são as possíveis desvantagens e riscos de tomar parte neste estudo?

A experiência de viver com uma doença crónica poderá aborrecê-lo ou deixá-lo triste. Se isto acontecer ser-lhe-á perguntado se gostaria de parar a observação. Se decidir parar a observação e desistir do estudo tal não afectará o seu cuidado na unidade de cuidados paliativos de nenhuma forma.

O que acontecerá aos resultados do estudo?

A informação recolhida durante a observação irá ser usada apenas no estudo e será tratada confidencialmente pela estudante de doutoramento e pelo seu supervisor o Professor Jonathan Gabe. Os resultados do estudo serão publicados na tese de doutoramento da estudante, bem como em artigos em jornais académicos. A estudante de doutoramento irá também apresentar os resultados do estudo em conferências académicas e não académicas. Um relatório será dado a si e aos seus familiares. Nunca será identificado em apresentações, publicações e relatórios, a menos que deseje manter a sua identidade.

Como e quem posso contactar em caso de dúvida?

Se tiver alguma dúvida acerca do estudo, por favor contacte a estudante de doutoramento:

Nome: Ana Patrícia Hilário

Morada: CIES-ISCTE, Edifício ISCTE, Av. das Forças Armadas, 1649-026 Lisboa

Telefone: (00351) 968 380 121

Email: patriciahilario@gmail.com

Poderá também contactar o supervisor da estudante de doutoramento:

Nome: Jonathan Gabe

Morada: Royal Holloway, University of London, Egham Hill, Egham, Surrey, TW20 0EX

Telephone: (0044) 178 444 314 4

Email: J.Gabe@rhul.ac.uk

Muito obrigada pelo tempo dispensado.

Poderá guardar este folheto informativo para referência.

Appendix 17 - Research Information Sheet E (Portuguese)

O corpo e as suas sombras: Um olhar sobre as experiências corporais dos doentes em cuidados paliativos

Folheto Informativo sobre a Observação Dos Doentes em Cuidados Paliativos e seus Familiares

Está a ser convidado para participar num estudo acerca das experiências dos doentes num serviço de cuidados paliativos. Antes de decidir é importante que compreenda as razões que levam à realização deste estudo e o que este envolve. Por favor leve o tempo que precisar para ler esta folha informativa. Se quiser obter mais informações ou se considerar que alguma informação não está suficientemente clara por favor pergunte-me. Estou aqui para ajudá-lo.

Quem organiza e financia este estudo?

Este estudo está a ser conduzido por Ana Patrícia Hilário, estudante de Doutoramento, no Departamento de Sociologia, da Royal Holloway-University of London, Egham, Reino Unido. Este estudo tem o apoio do Centro de Investigação e Estudos de Sociologia, do Instituto Superior de Ciências do Trabalho e da Empresa, Lisboa, Portugal. E é financiado pela Fundação para a Ciência e Tecnologia.

Qual é o objectivo deste estudo?

O objectivo do presente estudo é de contribuir para o conhecimento sobre as experiências dos doentes paliativos e dos seus cuidadores. A estudante de doutoramento está interessada em compreender a sua experiência de viver com uma doença e por conseguinte será dada atenção ao modo como a doença afecta a rotina diária do seu familiar. Este estudo pretende explorar a vivência quotidiana do seu familiar pelo que irá incidir sobre certos temas tais como: os cuidados que são prestados ao seu familiar, a autonomia física e a sua capacidade de controlo corporal do seu familiar, a imagem corporal do seu familiar, a identidade pessoal e social do seu familiar e o sentido de dignidade do seu familiar. Este estudo irá ajudar a melhorar os cuidados dados a futuros doentes.

O que acontecerá se decidir fazer parte do estudo?

Se decidir participar neste estudo ser-lhe-á pedido para ler e a assinar uma declaração de consentimento. Após ter obtido o seu consentimento a estudante de doutoramento irá observar as rotinas diárias do seu familiar. A informação recolhida será guardada num diário de campo de modo a que a estudante de doutoramento consiga recordar o que aconteceu. O seu nome e do seu familiar nunca será usado pelo que nunca ninguém o poderá identificar. Caso deseje ser identificado e deste modo manter a sua identidade, poderá fazê-lo. O seu direito e o direito do seu familiar ao anonimato, privacidade e confidencialidade será sempre respeitado. A declaração de consentimento será guardada separadamente da informação recolhida.

Quais são as possíveis desvantagens e riscos de tomar parte neste estudo?

A experiência de viver com uma doença crónica poderá aborrecer o seu familiar ou deixá-lo(a) triste. Se isto acontecer ser-lhe-á perguntado se gostaria de parar a observação. Se decidir parar a observação e desistir do estudo tal não afectará o cuidado do seu familiar na unidade de cuidados paliativos de nenhuma forma.

O que acontecerá aos resultados do estudo?

A informação recolhida durante a observação irá ser usada apenas no estudo e será tratada confidencialmente pela estudante de doutoramento e pelo seu supervisor o Professor Jonathan Gabe. Os resultados do estudo serão publicados na tese de doutoramento da estudante, bem como em artigos em jornais académicos. A estudante de doutoramento irá também apresentar os resultados do estudo em conferências académicas e não académicas. Um relatório será dado a si. Nunca será identificado em apresentações, publicações e relatórios, a menos que deseje manter a sua identidade. O seu familiar também nunca será identificado em qualquer uma das situações descritas.

Como e quem posso contactar em caso de dúvida?

Se tiver alguma dúvida acerca do estudo, por favor contacte a estudante de doutoramento:

Nome: Ana Patrícia Hilário

Morada: CIES-ISCTE, Edifício ISCTE, Av. das Forças Armadas, 1649-026 Lisboa

Telefone: (00351) 968 380 121

Email: patriciahilario@gmail.com

Poderá também contactar o supervisor da estudante de doutoramento:

Nome: Jonathan Gabe

Morada: Royal Holloway, University of London, Egham Hill, Egham, Surrey, TW20 0EX

Telephone: (0044) 178 444 314 4

Email: J.Gabe@rhul.ac.uk

Muito obrigada pelo tempo dispensado.

Poderá guardar este folheto informativo para referência.

Appendix 18 – Consent Form A (Portuguese)

O corpo e as suas sombras: Um olhar sobre as experiências corporais dos doentes em cuidados paliativos

Declaração de Consentimento para Entrevistar os Doentes em Cuidados Paliativos

A presente declaração enuncia os seus direitos enquanto participante no estudo sobre as experiências dos doentes em cuidados paliativos, conduzida por Ana Patrícia Hilário, estudante do Doutoramento em Sociologia, na Royal Holloway-University of London. Este estudo é apoiado pelo Centro de Investigação e Estudos Sociologia e financiado pela Fundação para a Ciência e Tecnologia.

1. Li (ou a Ana Patrícia leu) e compreendi a informação disponibilizada na folha []
informativa do estudo apresentada pela entrevistadora.
2. Foi-me dado a possibilidade de colocar questões acerca da natureza e do propósito []
do estudo. Essas questões foram satisfatoriamente respondidas.
3. Consinto ser entrevistado(a) no âmbito do estudo especificado acima e consinto []
que a entrevista seja gravada em suporte áudio.
4. Fui informado(a) de que a participação é voluntária e que poderei não responder a []
certas questões caso eu o deseje. Fui também informado(a) de que tenho a liberdade
de desistir a qualquer momento da entrevista. Caso desista de realizar a entrevista
não terei de apresentar qualquer justificação e o meu cuidado na unidade de
cuidados paliativos não será afectado.
5. Foi-me assegurado que a minha identificação pessoal neste estudo permanecerá []
anónima. A informação que disponibilizar na entrevista será confidencial e o meu
direito à privacidade será também respeitado pelo entrevistador.
6. Fui informado(a) que poderei manter a minha identidade caso o deseje. []
 - 6.1. Quero manter a minha identidade anónima através do uso de pseudónimo. []
 - 6.2. Não quero que a minha identidade seja anónima. O meu nome será mantido. []

Nome do(a) entrevistado(a): _____

Assinatura do(a) entrevistado(a): _____

7. Considero ter fornecido a informação necessária sobre o meu estudo, bem como ter dado a conhecer ao/à entrevistado/a as implicações em participar neste mesmo estudo. Acredito que o/a entrevistado/a compreendeu as implicações em participar no estudo. []

Nome do entrevistador: _____

Assinatura do entrevistador: _____

Data: _____

Appendix 19 – Consent Form B (Portuguese)

O corpo e as suas sombras: Um olhar sobre as experiências corporais dos doentes em cuidados paliativos

Declaração de Consentimento para Entrevistar os Familiares dos Doentes em Cuidados Paliativos

A presente declaração enuncia os seus direitos enquanto participante no estudo sobre as experiências dos doentes em cuidados paliativos, conduzida por Ana Patrícia Hilário, estudante do Doutoramento em Sociologia, na Royal Holloway-University of London. Este estudo é apoiado pelo Centro de Investigação e Estudos Sociologia e financiado pela Fundação para a Ciência e Tecnologia.

1. Li (ou a Ana Patrícia leu) e compreendi a informação disponibilizada na folha informativa do estudo apresentada pela entrevistadora.

2. Foi-me dado a possibilidade de colocar questões acerca da natureza e do propósito do estudo. Essas questões foram satisfatoriamente respondidas.

3. Consinto ser entrevistado(a) no âmbito do estudo especificado acima e consinto que a entrevista seja gravada em suporte áudio.

4. Fui informado(a) de que a participação é voluntária e que poderei não responder a certas questões caso eu o deseje. Fui também informado(a) de que tenho a liberdade de desistir a qualquer momento da entrevista. Caso desista de realizar a entrevista não terei de apresentar qualquer justificação e o cuidado aos meus familiares na unidade de cuidados paliativos não será afectado.

5. Foi-me assegurado que a minha identificação pessoal neste estudo permanecerá anónima. A informação que disponibilizar na entrevista será confidencial e o meu direito à privacidade será também respeitado pelo entrevistador.

6. Fui informado(a) que poderei manter a minha identidade caso o deseje.
 - 6.1. Quero manter a minha identidade anónima através do uso de pseudónimo.
 - 6.2. Não quero que a minha identidade seja anónima. O meu nome será mantido.

Nome do(a) entrevistado(a): _____

Assinatura do(a) entrevistado(a): _____

7. Considero ter fornecido a informação necessária sobre o meu estudo, bem como ter dado a conhecer ao/à entrevistado/a as implicações em participar neste mesmo estudo. []
Acredito que o/a entrevistado/a compreendeu as implicações em participar no estudo.

Nome do entrevistador: _____

Assinatura do entrevistador: _____

Data: _____

Appendix 20 – Consent Form C (Portuguese)

O corpo e as suas sombras: Um olhar sobre as experiências corporais dos doentes em cuidados paliativos

Declaração de Consentimento para Entrevistar os Profissionais de Saúde

A presente declaração enuncia os seus direitos enquanto participante no estudo sobre as experiências dos doentes em cuidados paliativos, conduzida por Ana Patrícia Hilário, estudante do Doutoramento em Sociologia, na Royal Holloway-University of London. Este estudo é apoiado pelo Centro de Investigação e Estudos Sociologia e financiado pela Fundação para a Ciência e Tecnologia.

1. Li (ou a Ana Patrícia leu) e compreendi a informação disponibilizada na folha []
informativa do estudo apresentada pela entrevistadora.
2. Foi-me dada a possibilidade de colocar questões acerca da natureza e do propósito []
do estudo. Essas questões foram satisfatoriamente respondidas.
3. Consinto ser entrevistado(a) no âmbito do estudo especificado acima e consinto []
que a entrevista seja gravada em suporte áudio.
4. Fui informado(a) de que a participação é voluntária e que poderei não responder a []
certas questões caso eu o deseje. Fui também informado(a) de que tenho a liberdade
de desistir a qualquer momento da entrevista. Caso desista de realizar a entrevista
não terei de apresentar qualquer justificação e o meu trabalho na unidade de
cuidados paliativos não será afectado.
5. Foi-me assegurado que a minha identificação pessoal neste estudo permanecerá []
anónima. A informação que disponibilizar na entrevista será confidencial e o meu
direito à privacidade será também respeitado pelo entrevistador.
6. Fui informado(a) que poderei manter a minha identidade caso o deseje. []
 - 6.1. Quero manter a minha identidade anónima através do uso de pseudónimo. []
 - 6.2. Não quero que a minha identidade seja anónima. O meu nome será mantido []

Nome do(a) entrevistado(a): _____

Assinatura do(a) entrevistado(a): _____

7. Considero ter fornecido a informação necessária sobre o meu estudo, bem como ter dado a conhecer ao/à entrevistado/a as implicações em participar neste mesmo estudo. Acredito que o/a entrevistado/a compreendeu as implicações em participar no estudo. []

Nome do entrevistador: _____

Assinatura do entrevistador: _____

Data: _____

Appendix 21 – Consent Form D (Portuguese)

O corpo e as suas sombras: Um olhar sobre as experiências corporais dos doentes em cuidados paliativos

Declaração de Consentimento para a Observação dos Doentes em Cuidados Paliativos

A presente declaração enuncia os seus direitos enquanto participante no estudo sobre as experiências dos doentes em cuidados paliativos, conduzida por Ana Patrícia Hilário, estudante do Doutoramento em Sociologia, na Royal Holloway-University of London. Este estudo é apoiado pelo Centro de Investigação e Estudos Sociologia e financiado pela Fundação para a Ciência e Tecnologia.

1. Li (ou a Ana Patrícia leu) e compreendi a informação disponibilizada na folha []
informativa do estudo apresentada pela entrevistadora.
 2. Foi-me dada a possibilidade de colocar questões acerca da natureza e do propósito []
do estudo. Essas questões foram satisfatoriamente respondidas.
 3. Consinto ser observado (a) no âmbito do estudo especificado acima e consinto que []
a observação seja recolhida num diário de campo.
 4. Fui informado(a) de que a participação é voluntária e que poderei não responder a []
certas questões caso eu o deseje. Fui também informado(a) de que tenho a liberdade
de desistir a qualquer momento da observação. Caso desista de participar na
observação não terei de apresentar qualquer justificação e o meu cuidado na unidade
de cuidados paliativos não será afectado.
 5. Foi-me assegurado que a minha identificação pessoal neste estudo permanecerá []
anónima. A informação que disponibilizar na observação será confidencial e o meu
direito à privacidade será também respeitado pelo observador.
 6. Fui informado(a) que poderei manter a minha identidade caso o deseje. []
 - 6.1. Quero manter a minha identidade anónima através do uso de pseudónimo. []
 - 6.2. Não quero que a minha identidade seja anónima. O meu nome será mantido []
- Nome do(a) observado(a): _____ []
- Assinatura do(a) observado(a): _____ []

7. Considero ter fornecido a informação necessária sobre o meu estudo, bem como ter dado a conhecer ao/à observado/a as implicações em participar neste mesmo estudo. Acredito que o/a observado/a compreendeu as implicações em participar no estudo. []

Nome do observador: _____

Assinatura do observador: _____

Data: _____

Appendix 22 – Consent Form E (Portuguese)

O corpo e as suas sombras: Um olhar sobre as experiências corporais dos doentes em cuidados paliativos

Declaração de Consentimento para a Observação dos Doentes em Cuidados Paliativos e seus Familiares

A presente declaração enuncia os seus direitos enquanto participante no estudo sobre as experiências dos doentes em cuidados paliativos, conduzida por Ana Patrícia Hilário, estudante do Doutoramento em Sociologia, na Royal Holloway-University of London. Este estudo é apoiado pelo Centro de Investigação e Estudos Sociologia e financiado pela Fundação para a Ciência e Tecnologia.

1. Li (ou a Ana Patrícia leu) e compreendi a informação disponibilizada na folha informativa do estudo apresentada pela entrevistadora. []
2. Foi-me dada a possibilidade de colocar questões acerca da natureza e do propósito do estudo. Essas questões foram satisfatoriamente respondidas. []
3. Consinto que eu e o meu familiar sejamos observados no âmbito do estudo especificado acima e consinto que a observação seja recolhida num diário de campo. []
4. Fui informado(a) de que a participação é voluntária e que eu e o meu familiar poderemos não responder a certas questões caso eu o deseje. Fui também informado(a) de que eu e o meu familiar temos a liberdade de desistir a qualquer momento da observação. Caso desista de participar na observação não terei de apresentar qualquer justificação e o cuidado do meu familiar na unidade de cuidados paliativos não será afectado. []
5. Foi-me assegurado que a minha identificação pessoal e do meu familiar neste estudo permanecerá anónima. A informação que disponibilizar na observação será confidencial e o meu direito à privacidade e do meu familiar será também respeitado pelo observador. []
6. Fui informado(a) que poderei manter a minha identidade caso o deseje. []

Nome do(a) observado(a): _____

Assinatura do(a) observado(a): _____

Nome do(a) familiar: _____

7. Considero ter fornecido a informação necessária sobre o meu estudo, bem como ter dado a conhecer ao/à observado/a as implicações em participar neste mesmo estudo. Acredito que o/a observado/a compreendeu as implicações em participar no estudo. []

Nome do observador: _____

Assinatura do observador: _____

Data: _____

Appendix 23 – Observation Topic Guide

1. Routines and practices of care

- 1.1. Reasons for patients' admission in the palliative care unit;
- 1.2. Emphasis given by professionals to physical aspects of care;
- 1.3. Emphasis given by professionals to symptom control;
- 1.4. Emphasis given by professionals to emotional aspects of care;
- 1.5. Patients' experiences of bodily care;
- 1.6. Relatives' involvement in patients' bodily care;
- 1.7. Reactions of professionals towards patients' bodily care;

2. Patients' physical autonomy and capacity for bodily control

- 2.1. Changes in patients' body in terms of functions brought about the disease;
- 2.2. Changes in patients' ability to act as autonomous agents brought about the disease;
- 2.3. Patients' experiences of loss of control over bodily functions;
- 2.4. Patients' experiences of poor mobility and lack of physical capabilities;
- 2.5. Patients' experiences of dependency upon others;
- 2.6. Changes in patients' social relationships due to their physical impairment;
- 2.7. Reactions of relatives and friends towards patients' physical impairment;

3. Patients' self-appearance

- 3.1. Changes in patients' identity brought about bodily disfigurement;
- 3.2. Changes in patients' body in terms of appearance brought about the disease;
- 3.3. Patients' feelings about his/her self-appearance;
- 3.4. Patients' interest on his/her self appearance;
- 3.5. Patients' sense of his/her body as physically and sexually attractive;
- 3.6. Reaction of relatives towards patients' self appearance;
- 3.7. Reactions of professionals towards patients' self appearance;

4. Patients' sense of self

- 4.1. Patients' interactions with relatives and friends,
- 4.2. Patients' interactions with health care professionals;
- 4.3. Importance given by patients to personal items and consumer goods;
- 4.4. Relatives perceptions of patients' life as having lost any positive value;
- 4.5. Relatives' beliefs that the patient should be treated as a person;
- 4.6. Relatives' feelings of patients as being as good as dead;
- 4.7. Patients' feelings of life as having lost any positive value;

5. Patients' dignity

- 5.1. Emphasis given by professionals to the maintenance of patients' dignity;
- 5.2. Relatives concerns about the maintenance of patients' dignity;
- 5.3. Strategies employed by professionals to relief patients' from suffering;
- 5.4. The use and practice of sedation by palliative care professionals;
- 5.5. Patients' changing perceptions of space and time;
- 5.6. Patients' ability to recognize others;
- 5.7. Level of patients' consciousness and contact with the environment;

Appendix 24- Interview Topic Guide A

Interview Topic Guide for Palliative Care Patients

1. Approaching the topic

- 1.1. Extent of knowledge about the philosophy and practice of palliative care.

2. Patients' illness experience

- 2.1. The discovery of initial symptoms;
- 2.2. Patients' feelings about his/her illness and the symptoms experienced;
- 2.3. The disclosure of diagnosis;
- 2.4. Changes in patients' life brought about the disease;
- 2.5. Patients' feelings about the disruption of taken-for-granted assumptions;
- 2.6. Patients' awareness of clinical prognosis and impending death.

3. Routines and practices of care

- 3.1. Reasons for admission in the palliative care unit;
- 3.2. Importance given by patients' to physical aspects of care;
- 3.3. Importance given by patients' to symptom control;
- 3.4. Importance given by patients' to emotional aspects of care;
- 3.5. Patients' feelings about his/her bodily care;

4. Patients' physical autonomy and capacity for bodily control

- 4.1. Changes in patients' body in terms of functions brought about the disease;
- 4.2. Experiences of loss of control over bodily functions
- 4.3. Experiences of poor mobility and lack of physical capabilities;
- 4.4. Experiences of dependency upon others;
- 4.5. Experiences of becoming a burden to family and friends;

5. Patients' self-appearance

- 5.1. Changes in patients' body in terms of appearance brought about the disease;
- 5.2. Patients' feelings about his/her body image and self-appearance;
- 5.3. Importance given by patients' to their body image and self-appearance;
- 5.4. Changes of patients' sense of his/her body as physically and sexually attractive brought about the disease;
- 5.5. Reactions of others towards patients' physical appearance.

6. Patients' sense of self

- 6.1. Importance given by patients' to interactions with palliative care professionals;
- 6.2. Importance given by patients' to interactions with relatives and friends;
- 6.3 Patients' feelings of social isolation due to their debilitating condition;
- 6.4. Patients' feelings of loss of self-worth due to their debilitating condition;
- 6.5. Patients' perceptions of life as having lost any positive value;

7. Patients' dignity

- 7.1. Patient's perceptions of the meaning of dignity;
- 7.2. Illness' impact on patients' dignity;
- 7.3. Aspects that may give dignity to patients;
- 7.4. Aspects that may treat patient's dignity
- 7.5. Patient's concerns around dignity;
- 7.6. Patient's concerns around other aspects of his/her life.

Personal information

Age

Sex

Last occupation

Ethnicity

Illness

Length of time in the palliative care unit

Date

Appendix 25 – Interview Topic Guide B

Interview Topic Guide for Relatives of Palliative Care Patients

1. Introduction to the interview topic

- 1.1. Extent of knowledge about the philosophy and practice of palliative care.

2. Relatives views about patients' illness experience

- 2.1. The discovery of initial symptoms;
- 2.2. The disclosure of diagnosis and family reactions;
- 2.3. Changes in patients' life brought about the disease;
- 2.4. Relatives' involvement in patients' care;

3. Routines and practices of care

- 3.1. Reasons for patient's admission in the palliative care unit;
- 3.2. Importance given by relatives to the physical aspects of care;
- 3.3. Importance given by relatives to symptom control;
- 3.4. Importance given by relatives to the emotional aspects of care;
- 3.5. Relatives' feelings about patient's bodily care;

4. Relatives views about patients' physical autonomy and capacity for bodily control

- 4.1. Changes in patients' body in terms of physical autonomy and capacity for bodily control brought about the disease;
- 4.2. Reaction of relatives towards patients' physical impairment;
- 4.3. Relatives feelings about patients' physical impairment;
- 4.4. Relatives experiences of patients' lack of bodily control;
- 4.5. Relatives experiences of patients' dependency upon them;
- 4.6. Relatives experiences of patients' becoming a burden to them;

5. Relatives views about patient's self-appearance

- 5.1. Changes in patients' body in terms of appearance brought about the disease;
- 5.2. Importance given by patients to their body image and self-appearance before and after the illness experience;
- 5.3. Reaction of patients towards their physical appearance;
- 5.4. Reaction of relatives towards patients' physical appearance;
- 5.5. Patients' feelings about their body image and self-appearance;
- 5.6. Relatives' feelings about patients' body image and self-appearance.

6. Relatives views about patients' sense of self

- 6.1. Relatives interaction with patient's;
- 6.2. Patients' interaction with relatives;
- 6.3. Patients' ability to recognize others;
- 6.4. Patients' changing perceptions of space and time;
- 6.5. Relatives beliefs that the patient should be treated as a person;
- 6.6. Relatives perceptions of patients' life as having lost any positive value;

7. Patients' dignity

- 7.1. Relatives perceptions of the meaning of dignity;
- 7.2. Illness' impact on patients' dignity;
- 7.3. Aspects that may give dignity to patients;
- 7.4. Aspects that may threaten patient's dignity;
- 7.5. Relatives concerns around patient's dignity;
- 7.6. Relatives concerns around patient's life;
- 7.7. Relatives perceptions of a good death.

Personal information

Age

Sex

Current/last occupation

Ethnicity

Kinship

Patients' illness

Patients' age

Patients' sex

Patients' length of time in the palliative care unit

Date

Appendix 26 – Interview Topic Guide C

Interview Topic Guide for Palliative Care Professionals

1. Approaching the topic

- 1.1. Extent of knowledge about the philosophy and practice of palliative care;

2. Routines and practices of care

- 2.1. Reasons for patients' admission in the palliative care unit;
- 2.2. Importance given by professionals to physical aspects of care;
- 2.3. Importance given by professionals to symptom control;
- 2.4. Importance given by professionals to emotional aspects of care;
- 2.5. Care aspects that professionals find hard to cope with;
- 2.6. Professionals' feelings about the ubiquitous presence of bodily decay and death;

3. Professionals views about patients' physical autonomy and capacity of bodily control

- 3.1. Changes in patients' ability to act as an autonomous agent brought about the disease;
- 3.2. Changes in patients' capacity of bodily control brought about the disease;
- 3.3. Changes in patient's physical mobility and physical capabilities brought about the disease;
- 3.4. Patients' experiences of dependency upon others;
- 3.5. Changes in patients' social relationships due to their physical impairment;
- 3.6. Reactions of relatives and friends towards patients' physical impairment;

4. Professionals views about patients' self-appearance

- 4.1. Changes in patients' self-appearance brought about the disease;
- 4.2. Reaction of patients towards their self-appearance;
- 4.3. Patients' feelings about their self-appearance;
- 4.4. Importance given by patients to their self-appearance;

- 4.5. Reaction of relatives towards patients' self-appearance;
- 4.6. Reaction of professionals towards patient's self-appearance;

5. Professionals views about patients' sense of self

- 5.1. Patients' interaction with relatives;
- 5.2. Patients' interaction with professionals;
- 5.3. Patients' changing perceptions of space and time;
- 5.4. Patient's level of consciousness and contact with the environment;
- 5.5. Patient's sense of self worth;
- 5.6. Professionals perceptions of patients' life as having lost any positive value;

6. Professionals views about patients' dignity

- 6.1. Professionals perceptions of the meaning of dignity;
- 6.2. Illness' impact on patients' dignity;
- 6.3. Aspects that may give dignity to patients;
- 6.4. Aspects that may threat patient's dignity;
- 6.5. Professionals concerns around patient's dignity;
- 6.6. Professionals concerns around patient's sedation;
- 6.7. Professionals perceptions of a good death;

Personal information

Age

Sex

Speciality

Length of time working in palliative care

Date

Appendix 27 – List of Codes

- 1 ability to recognise others
- 2 admission on the palliative care unit
- 3 awareness of dying
- 4 bad deaths
- 5 biographical disruption
- 6 bodily care
- 7 bodily changes and death proximity
- 8 bodily identification
- 9 burden to others
- 10 changes in social relation
- 11 comparison between palliative care and acute care
- 12 contact with environment
- 13 death as a bless
- 14 dependency upon others
- 15 difficult aspects
- 16 difficult aspects of bodily changes to professionals
- 17 dignity
- 18 dignified care
- 19 emotional care
- 20 emotional labour
- 21 experience of poor mobility
- 22 family role
- 23 fear of death and dying
- 24 gender
- 25 gender and loss of bodily control
- 26 gender differences in terms of bodily changes
- 27 good death
- 28 hope
- 29 illness impact on dignity

- 30 importance given by patients to their self-appearance
- 31 importance given by the team to patient's bodily changes
- 32 importance given to food
- 33 inability to communicate
- 34 inability to do and act
- 35 individuality
- 36 influences on dignity
- 37 interaction with professionals
- 38 interaction with relatives
- 39 intimacy
- 40 knowledge of palliative care
- 41 level of conscious
- 42 levels of bodily changes
- 43 loss of control over the body
- 44 loss of personhood
- 45 medical responses to suffering
- 46 patient's reactions towards bodily changes
- 47 patient's reactions towards loss of bodily control
- 48 personally facing death
- 49 physical care
- 50 professionals reactions towards patient's self-appearance
- 51 relatives feelings about changes in patient's self-appearance
- 52 relatives reactions towards changes in patient's self-appearance
- 53 relatives reactions towards patient's loss of bodily control
- 54 self value
- 55 sense of space
- 56 sense of time
- 57 social isolation
- 58 stigma
- 59 suffering
- 60 threats to dignity

61 use of diaper

62 use of sedation

Appendix 28 – A detailed description of research participants

Brian, aged 45, had been diagnosed with colon cancer in 2008. He also had liver metastases. After a surgical procedure Brian developed an infection and ended losing all his fingers. He has been admitted into the in-patient unit in September 2009. He was able to walk by himself and did not need help for daily living activities. However he suffered from lethargy and thereby became tired very easily. He also suffered from anxiety. Before I left the fieldwork Brian was discharged as he was independent enough at the time. He wanted to return home so he could spend more time with his wife and eight-year-old daughter.

Brenda, aged 65, was admitted to the in-patient unit on April 2010. She had been diagnosed as having a Merkel Cell carcinoma in December 2008, two months after the death of her husband. The radiotherapy and surgical treatment had not been successful. Brenda's cancer spread throughout her body and as a result she developed several ulcers. Brenda has two adult daughters but they were not able to take care of her at home. She was able to walk by herself, albeit she needed help for daily-living activities such as bathing and dressing. At the time I left the field work, Brenda was still independent and very talkative.

Brad, aged 58, had been diagnosed with prostate cancer in 2008. He was married and had a daughter and a son. The radiotherapy and chemotherapy had not been successful. He was admitted in the in-patient unit on August 2010. Prior his admission he had been at the hospital. He had lost the strength of both his legs and thereby was bed-bound.

He also had to use a diaper to contain leakage. Brad remained very talkative until his death, in the end of September 2010 - while I was doing fieldwork.

Beatrice, aged 68, had been diagnosed as having an occult tumor (i.e. a tumor that was hidden or so small that it couldn't be found) on April 2009. Prior hospice admission she had suffered from severe pain. Beatrice had also lost a considerable amount of weight. She suffered from lethargy. Beatrice had bone metastases and thereby she had lost her bodily mobility. She also suffered from lung metastases. Beatrice has become incontinent and thereby had to use diapers to contain leakage. While Beatrice was at home she was cared by her husband Albert, who has married her forty years ago. They both had a son who had recently moved from their home to live with his girlfriend. Beatrice also had three sisters, who lived nearby and helped her whenever possible. At the end of July, Beatrice's condition began to deteriorate and she was admitted to the local hospital. When Beatrice was discharged from the hospital, at the beginning of August 2009, and because Albert was no longer able to care for his wife at home, she was admitted to the in-patient unit. Beatrice was very well humored and was extremely talkative. In the weeks prior her death, Beatrice became very confused and was no longer able to recognize her loved ones. Beatrice died at the beginning of January 2011 - while I was doing fieldwork. I was able to interview Beatrice's husband, **Albert**, aged 66, two months prior her death.

Bella, aged 72, had been diagnosed with ovarian cancer. She was divorced and had a daughter and a son from her previous marriage. She also had grandsons. The chemotherapy and the surgery had not been successful. Before she was admitted into the in-patient unit Bella had been living in a nursing home. However her condition began to

deteriorate and thereby her family decided to look for a place where she could have proper care. Bella was admitted into the in-patient unit in the end of November 2010. Bella had lost the sensitivity of her fingers and thereby she needed help to dress and to have a bath. Nevertheless she was able to walk by herself and to go to the toilet alone. She enjoyed smoking outside – at the unit garden. In the days prior her death she became very weak and spend most of the time sleeping. She died in the beginning of January 2011.

Ben, aged 52, had been diagnosed as having cancer of the esophagus at the end of 2009. The radiotherapy and chemotherapy had not been unsuccessful. His wife had died three years ago in an accident. He hadn't any relatives. Ben suffered from lethargy and thus was no longer able to work and to be alone at home. He also had lost the strength in both hands. In October 2010, Ben was admitted to the local hospital. A month after, in December 2010, he was admitted into the in-patient hospice unit. Ben used to go outside the unit - namely to the garden - three times per day to smoke a cigarette. He also enjoyed reading the newspaper after lunch. He developed a close relationship with Bob. Ben was still able to walk by himself at the time I left the fieldwork, in March 2011.

Bob, aged 59, had been diagnosed as having a tumor in the liver on August 2010, after being admitted to the local hospital due to abdominal pain. Bob had taken early retirement and lived with his ex-wife and daughter, who suffered from a mental illness. Because of his lack of proper support at home, Bob spent five months at the hospital until he was admitted into the in-patient unit on December 2010. Because Bob's cancer had spread to his spine he had become paralyzed below the waist and thus become

wheelchair bound. He had also become incontinent and thus had to use diapers to contain leakage. He needed support for bathing. Bob was able to smoke outside with the help of his well-chair. At the time I left the fieldwork, he was still able to do it and his condition remained stable.

Billy, aged 78, had been diagnosed as having cancer of the lung. The radiotherapy and chemotherapy had not been successful. Prior his admission at the in-patient hospice unit in January 2011, Billy had been living at his daughter's home. He also had a grandson who helped him with the daily living activities when he was at his daughter's home. He had lost the strength of both his arms and legs and thereby was bed-bounded. He needed the help of staff to use the toilet, as well as to have a bath. When I left the fieldwork Billy was still very talkative.

Becky, aged 78, had been diagnosed as having ovarian cancer on 2005. Following chemotherapy and surgery it was believed that she was cured. However, in 2007, new tests revealed that her cancer had spread throughout her body. The chemotherapy was again unsuccessful. In 2010 due to an abdominal infection Becky was admitted to the local hospital. Her condition began to deteriorate. Becky had lost her capacity to control her urine and feces. When her abdominal infection was controlled, Becky was discharged from the hospital. At the time, Becky was admitted in a nursing home. Becky had never married and did not have any children. Her sister-in-law and her brother were her only relatives. At the end of 2010, after three months in the nursing home, Becky was admitted to the in-patient unit. Becky had lost her bodily mobility so she had become bed bound. Because she was incontinent she had to use diapers to

contain urine and feces. At the time I left the fieldwork, Becky's physical condition remained stable. I was able to interview her sister-in-law, **Angela**.

Bridget, aged 69, had been diagnosed as having a cancer of the esophagus. She was admitted into the in-patient unit in February 2010. Prior to her admission, she had been living at home with her husband and her son. She also had a daughter, who had two sons. Because of her illness, as well as her lack of nutritional support at home, Bridget had lost a considerable amount of weight and looked like a 'living corpse'. Indeed Bridget weight loss was so dramatic that according to staff it could lead to her impending death. She also suffered from lethargy. Bridget had lost her bodily mobility and thereby had become bed bound. She had to use diapers to contain leakage. Bridget was still very talkative at the time I left the field work.

Abby's husband, aged 58, had been diagnosed with lung cancer in the beginning of 2006. The chemotherapy, radiotherapy and surgery had not been successful. His condition deteriorated and in the beginning of 2007 he had been diagnosed with brain metastases. He lost his bodily mobility and became bed-bounded. He had to use diapers because he had lost the control of leakage. His wife was no longer able to take care of him at home as she was emotionally very tired and thereby he was admitted into the in-patient unit in the beginning of 2010. He suffered from periods of anger and mental confusion. He progressively became very weak and spent most of the time sleeping. He died two weeks after I interviewed Abby.

Anna's mother, aged 77, widow, had been diagnosed with spongiform encephalopathy in June 2009. She began to suffer from hallucinations and lost her bodily mobility. She lost the control of urine and feces and had to use diapers. Her condition deteriorated and

she entered in coma. Five months after the diagnosis she was admitted into the in-patient unit. She had been in a vegetative state since then. She was feed through a nasogastric tube inserted in her nose. Her condition remained stable at the time I left the field work.

Alvin's wife, aged 70, had been diagnosed with a multiple myeloma in the beginning of 2009. She became very weak and thereby bed-bounded. She also had to use diapers to control leakage. Her husband was not able to take care of her at home and thus she was admitted into the in-patient unit in November 2009. After six months of being at the unit her condition improved as her pain was controlled and she was able to walk by herself. Her wish was to go back to her home and thereby the team decided to discharge her in April 2010.

Alan's wife, aged 80, had been diagnosed with a non-Hodkin Lymphoma in March 2009. The chemotherapy and radiotherapy had not been successful. Her condition began to deteriorate and she lost her bodily mobility. Because she became bed-bounded she had to use diapers to control leakage. She had also lost her ability to eat and had to be feed through a nasogastric tube. She began to suffer from mutism and thereby she did not communicate with others. Her husband was no longer able to take care of her at home so she was admitted into the in-patient unit in January 2010. At the time I left the fieldwork her condition was stable.

Addison's husband, aged 58, had been diagnosed with colon cancer, as well as with lung and bone metastases in September 2009. The chemotherapy had not been successful. His condition began to deteriorate and he lost his bodily mobility. He became bed-bounded and had to use diapers to control leakage. His wife was not able to

take care of him at home and he was admitted into the in-patient unit in March 2010. He died two months later.

Adriana's husband, aged 82, had been in a vegetative state since 2008 after a fall which had caused major brain damages. He started to have seizures. He became bed-bounded and lost his ability to communicate. He had to be feed through a nasogastric tube. Prior his admission into the in-patient unit, in the beginning of 2010, he had been in a private hospital. His condition was stable at the time I left the fieldwork.

Alice's husband, aged 63, had been diagnosed with an esophageal cancer in 2008. The chemotherapy and radiotherapy had not been successful. He developed lung metastases. His condition began to deteriorate and he had had a stroke. He lost his bodily mobility and had to use diapers to control leakage. He also lost his ability to communicate. His wife was not able to take care of him at home and thereby he was admitted into the in-patient unit in May 2009. He died one month after I conducted the interview with his wife.

Andie's wife, aged 62, had been diagnosed with a malignant glioma in April 2009. The chemotherapy and surgery had not been successful and her condition began to deteriorate. She had a pulmonary embolism. She then lost her bodily mobility and became well-chair bound. It became increasingly difficult for her husband to take care of her and thereby she was admitted into the in-patient unit in February 2010. At the time I left the fieldwork her condition was stable.

Alicia's cousin, widow, aged 77, had been diagnosed with colon cancer in July 2008. The chemotherapy and surgery had not been successful. She developed lung and liver

metastases. Her condition began to deteriorate and her family was not able to take care of her at home. She was admitted into the in-patient unit in November 2009. She was able to walk by herself but needed help for daily living activities such as bathing and dressing. She died in June 2010, one month after I conducted the interview with her cousin.

Amelia's mother, aged 96, had been in a vegetative state since April 2009. She had had a stroke and thereby become paralyzed and lost her ability to communicate. She had to use diapers to control leakage and had to be feed through a nasogastric tube. Her family was not able to take care of her at home and thereby she was admitted into the in-patient unit in May 2009. At the time I left the fieldwork her condition remained stable.

Anastasia's husband, aged 69, had been diagnosed with prostate cancer in 2000. In September 2009 he began to suffer from strong headaches as a consequence of brain metastases. The chemotherapy, radiotherapy and the surgery had not been successful. He developed bone metastases and thereby had lost his bodily mobility. He also had to use diapers to control leakage. He was no longer able to communicate. He was admitted into the in-patient unit in May 2010 as his wife was no longer able to care for him at home. Anastasia felt physically and emotionally exhausted. He died in the end of October 2010 - while I was doing fieldwork.

Adele's father, aged 87, widow, had been diagnosed with bladder cancer in 2007. His condition began to deteriorate and he was admitted into the in-patient unit in August 2010. Albeit he had lost the strength of both his legs he was still able to walk by himself. He nevertheless needed the help of others for bathing and dressing. He had to use diapers to control leakage. His three daughters worked and thereby could not take

care of him. The admission into the in-patient unit seemed to them the most reasonable option. During the time he had been at the in-patient unit he was able to spend two weekends at home with his daughters. He was very talkative with staff as well as with the other patients. Three days prior his death he began to feel very weak and became bed-bounded. He died in October 2010 - while I was doing fieldwork.

Aaron's father, aged 85, married, had been diagnosed with rectum cancer in June 2009. The radiotherapy and chemotherapy had not been successful. He developed liver metastases and lost his bodily mobility. Aaron's father became bed-bound and had to use diapers to control leakage. He was able to communicate albeit he felt very tired and as a result spent most of the time sleeping. His wife was no longer able to take care of him at home and thereby he was admitted into the in-patient unit in November 2010. His son and wife left their home and came to live with his grandson who had a house nearby so they could support him. His condition rapidly deteriorated and he died in the end of the month - while I was doing fieldwork.

Alphonso's mother, aged 71, married, with three sons, had been diagnosed with a chordoma (i.e. a rare bone cancer) in 1997. The radiotherapy and chemotherapy had not been successful. The 19 surgeries that she had made had also not removed the tumour. In 2003 she lost her bowel and had to wear a colostomy bag. More recently she developed bone metastases and thereby had lost her bodily mobility. Her condition began to deteriorate and her family was no longer able to care for her at home. She was admitted into the in-patient unit in October 2010. At the time of her admission she suffered from hallucinations and screamed most of time. She was paranoid and confused. She moved in and out of coma rapidly. While in some periods she was able to

recognise her family members and interact with them, in other periods she was not able to do it. She died in the beginning of December 2010 - while I was doing fieldwork.

Amanda's mother, aged 66, widow, with two daughters and one son, had been diagnosed with tongue cancer in 1992. She had done chemotherapy and the 3 surgeries. Her condition began to deteriorate in April 2010 and she had to leave her house and move to her daughter's home. The malignant wound on her face increased and limited her verbal communication with others as it became very difficult to understand her. In July she began to suffer from severe pain in her throat and was no longer able to eat. A nasogastric tube was then inserted through her stoma so she could be feed. Amanda felt emotionally very tired and was no longer able to take care for her mother at home. She was then admitted into the in-patient unit in the end of October 2010. At the time of her admission, Amanda's mother was able to walk independently within the unit. She gradually lost the strength of her legs and thereby spent most the time in her bedroom. The nasogastric tube also developed some problems and the palliative care team was not able to feed her properly, despite all the efforts they made. Amanda's mother became very weak and bed-bounded. She died in the beginning of January 2011 - while I was doing fieldwork.

Antonia's husband, aged 66, had been diagnosed with brain cancer in February 2010. The radiotherapy and chemotherapy had not been successful. He became bed-bounded and has to use diapers to control leakage. His condition began to deteriorate and his wife was no longer able to take care of him at home. He was admitted into the in-patient unit in January 2011. He was not able to communicate and spent most of the time

sleeping. At the time I left the fieldwork his condition was stable. He eventually died at the in-patient unit.

Andrea's husband, aged 72, had been diagnosed with lung cancer in January 2010. He had done chemotherapy, radiotherapy and surgery. In August he lost the strength of both his legs and became bed-bounded. He also had to use diapers to control leakage. He developed brain metastases and as a consequent from time to time had seizures. His condition began to deteriorate and his wife was no longer able to take care of him at home. He was admitted into the in-patient unit in February 2011. He spent most of the time sleeping and his ability to communicate was very limited. His condition was stable at the time I left the fieldwork.

April's mother, aged 64, had been diagnosed with breast cancer in 2000. She had done chemotherapy, radiotherapy and surgery. In the end of 2010 she began to suffer from severe pain and had been diagnosed with bone metastases. She became bed-bounded and had to use diapers to control leakage. Her family was not able to take care of her at home. Prior her admission into the in-patient unit in February 2011 she had been at the local hospital. Her condition remained stable at the time I left the fieldwork.