

CIES e-Working Paper N.º 122/2012

**What about dignity?**  
**The meaning and experience of terminally ill patients**

ANA PATRÍCIA HILÁRIO

*CIES e-Working Papers* (ISSN 1647-0893)

Av. das Forças Armadas, Edifício ISCTE, 1649-026 LISBOA, PORTUGAL, [cies@iscte.pt](mailto:cies@iscte.pt)

**Ana Patrícia Hilário** holds a degree in Sociology and Planning from Lisbon University Institute. She is currently preparing her PhD in Sociology at Royal Holloway, University of London, and is carrying out research as a doctoral fellow at the Centre for Research and Studies in Sociology (CIES), Lisbon University Institute. Her main research interests focus on the sociology of health and illness, sociology of the body and sociology of death and dying. [patriciahilario@gmail.com](mailto:patriciahilario@gmail.com)

**Abstract:** While a number of studies have focused on the palliative care ideal of dying with dignity, less attention has been given to the factors that are likely to influence the experience of dignity at the end of life. What has been neglected in these studies is the impact that the inability to act independently has upon a terminally ill patient's sense of dignity. The present study aims to understand the ways in which the dignity of terminally ill patients is affected when they lose their ability to act as autonomous agents. Participant observation was conducted over a ten-month period in two Portuguese palliative care units for cancer and non-cancer patients, to complement interviewing techniques. A total of ten palliative care patients were interviewed for research purposes. Interviews were also conducted with twenty family members and twenty palliative care professionals. The preliminary results of this ongoing doctoral research will be presented.

**Key words:** dignity, dignified care, dying people, end of life

## **Introduction**

By using a framework that examines the ways in which the process of bodily deterioration and decay is experienced by terminally ill patients, the present study sheds light on the importance of looking at the concept of dignity in order to understand the impact that the loss of bodily autonomy has on a patient's self-identity. While a number of studies have focused on the palliative care ideal of dying with dignity, less attention was given to the factors that are likely to influence the experience of dignity at the end of life. Indeed, most studies have ignored the physical vulnerability of those who suffer from a terminal illness. What has clearly been neglected in these studies is how the inability to act independently leads to a sense of loss of dignity in terminally ill patients. Thus, there is a need to explore the extent to which the dignity of terminally ill patients is affected when they lose their ability to act as autonomous agents.

This study adopted an ethnographic approach. Participant observation was conducted over ten months in two Portuguese palliative care units for cancer and non-cancer patients (i.e. five months in each unit) to complement interviewing techniques. A total of ten palliative care patients were interviewed for research purposes. Interviews were also conducted with twenty family members and twenty palliative care professionals. Research participants were informed about the aims, methods, benefits and risks of the study. Informed consent was obtained from the terminally ill patients, their family members and the palliative care professionals on the understanding that participation was voluntary and could be withdrawn at any time. The patients' rights to anonymity, privacy and confidentiality were respected by the researcher.

The preliminary results of this ongoing doctoral research will also be presented here. The first section of this study analyses the importance of bodily autonomy to the narratives on dignity. The principles of the philosophy and practice of palliative care and therefore the ideal of dignified care are discussed in the second section. Having outlined the scope of this study, we shall now turn to a more detailed consideration of the meaning and definition of dignity.

## **The meaning and definition of dignity**

This section sheds light on the importance of looking at the concept of dignity to understand the impact of the process of bodily deterioration and decay on the self-identity of terminally ill patients. Although the concept of dignity is difficult to define (Tadd, 2006), some authors have identified two meanings (Nordenfelt, 2004). It can be described, on the one hand, as the dignity that we attach to ourselves as integrated and autonomous persons and, on the other hand, it can be understood as an inherent value that belongs to every human being by virtue of being human (Nordenfelt, 2009). The former – the ‘dignity of identity’ – is seen as a consequence of the recognition of the latter – ‘human dignity’ – and is experienced through interaction (Jacobson, 2007). It is the feelings of recognition or rejection that give meaning to the experiential perception of dignity (Calnan et al, 2006). Dignity may be a salient issue in an end-of-life situation because it is a time when terminally ill patients have limited opportunities for participation and/or social recognition (ibid). Terminally ill patients may lose their ability to act independently and thereby become dependent on the help of others.

For this reason, it could be argued that when terminally ill patients lose their bodily ability to perform tasks by themselves they may feel a loss of dignity. Indeed, when asked to describe the impact of their inability to act independently on their sense of dignity, some of the patients with a terminal illness expressed negative feelings about it. For example, Brenda, who was very afraid of being a burden on her two adult daughters, indicated that she preferred to die than depend on the help of others. Brenda suggested that there is a strong relationship between an individual’s ability to act by themselves and their status as a person:

“Interviewer: What may affect your dignity? Do you think it’s being dependent on other people?”

Interviewee: Yes, of course! I think when we get to this point the best is to die.

Interviewer: Are you speaking in terms of physical suffering?

Interviewee: Yes, because, if the person is dependent for everything, can you tell me what the person is still doing here? If you are in pain, if you are dependent on others, I think this is not a life! For me it’s more a sacrifice!

Interviewer: The maintenance of your dignity is an issue that worries you?

Interviewee: Yes!

Interviewer: In what sense?

Interviewee: It concerns me. As I have told you, I don't want to be dependent upon others. I don't want to see myself and say: poor me! With that suffering! With that thing! This shocks me!

Interviewer: Are you talking about having pain?

Interviewee: Having pain and at the same time feeling this way. Of seeing myself dependent. There are people who become totally dependent. They cannot do anything. For me this is more vegetating than living.

(Brenda, dying patient)

What is clearly being suggested by this respondent is that the sense of dignity is incompatible with living within an unbounded dying body. This finding echoes previous studies on dignity. Stress and Kissane (2001) claimed that the notion of the shameful body was deeply interwoven with the response by terminally ill patients to the breakdown of their bodily integrity. Elliot and Olver (2008) also demonstrated that the biological changes occurring alongside the dying process were more often than not seen by these patients as distasteful and undignified. In addition, Enes noted that bodily control was a major feature of the meaning of dignity for terminally ill patients. Indeed the loss of control over the body was understood by several terminally ill patients and their family members as a fundamental loss of dignity. For instance, when describing the changes in her husband's body after a stroke episode, Adriana indicated that the lack of self-control was likely to have an impact on the patient's sense of dignity:

“Of course it has an impact. Firstly, nobody likes to wear diapers. It's the first thing that I think patients refuse. But those who accept the disease must start by accepting this. Then, the fact of being cleaned by others. Of not being able to clean themselves. All this has an impact on their sense of dignity.”

(Adele, wife)

Similarly, Beatrice, who was bed-bound due to her clinical condition, explained the importance of having control over her body for the maintenance of her sense of dignity:

“Interviewer: Do you think that the fact that you are not able to act in independent ways has an impact upon your sense of dignity?”

Interviewee: Yes.

Interviewer: Why?

Interviewee: Because I am here. I cannot do anything. Just be in bed.

Interviewer: This has an impact upon your sense of dignity?

Interviewee: Yes.

Interviewer: Why?

Interviewee: Because I miss doing my things. I miss seeing my things.

Interviewer: Do you feel less of a person because you cannot do your things?

Interviewee: Yes, I do.

Interviewer: Can you tell me why?

Interviewee: Because I cannot do anything. I am not able to move. I am not able to do certain things.”

(Beatrice, dying patient)

This statement is very interesting in that it shows the importance of the bodily ability to act as an autonomous agent for the maintenance of the dignity of those who are very ill and at the end of their lives. Authors such as Lawton (2000: 101) have argued that because selfhood is likely to be dependent upon a notion of agency, agency is likely to be dependent upon a notion of action. That is, the capacity of individuals to act by themselves. Thus, our findings reveal an individualistic narrative on dignity, which seems to reflect the contemporary Western value of the individual's responsibility (Giddens, 1991) for his or her own care (Seale et al, 1997). For instance, Amelia indicated that her mother, who was in coma for two years after a stroke episode, can no longer be considered a person because of her inability to act independently:

“A person who is... let's admit it... a vegetable. That has no thought. That has no autonomy. That has no pleasure in being alive. She's a thing. She's no longer a person.”

(Amelia, daughter)

What this respondent is suggesting is that the dying process and the disease itself threaten the individual's identity and dignity. In the case of a terminal illness, a patient's self-respect can be shattered by the nature of the disease itself as well as by the attitudes and behaviours of others. When people facing a terminal illness feel humiliated or insulted or are treated as objects, they are likely to lose their dignity. Nordenfelt (2009: 33) called it the

dignity of identity and described it as the dignity that we attach to ourselves as integrated and autonomous persons with our relationships with other human beings. Feelings of humiliation or embarrassment related to a loss of autonomy and independence more often than not affect our patients' sense of self-worth and thereby their dignity of identity. For example, Capri described the dignity of identity in relation to Barney, a 46-year-old brain cancer victim who was the father of two children and once a recognised lawyer:

“We have a gentleman that has moments of real lucidity and others without. When he is lucid we can see his suffering. Some days ago I went to his room and he was uncovered. He was only using a diaper. He suddenly saw me and said: I am not presentable. He said to me: I am not presentable. I'm here is this state. This affected his dignity. I said: Look, I'll cover you with the sheet. After this he felt better. But I felt a great sadness in him. Because I was encroaching on his dignity. Because he was using diapers. He also has a tumour and sometimes says things... Sometimes he is in a state of total confusion. Because he has had an operation and half of his brain doesn't work. From time to time a light switches on. He feels affected in his dignity, of course.”

(Capri, spiritual and religious assistant)

What this respondent is clearly showing is that, in addition to the inability to act independently, the inability to maintain independence in terms of cognitive acuity is experienced by terminally ill patients as a fundamental loss of dignity (Chochinov, 2006). Calnan et al (2006) found that keeping control both physically and mentally is a major issue for vulnerable people and so this is likely to influence their sense of dignity. The idea that the loss of autonomy is likely to have an impact on a terminally ill patient's sense of dignity was explicitly mentioned by Chloe:

“Losing the ability to be a person with their own will. No longer having the right to have an opinion. This from my point of view affects their sense of dignity.”

(Chloe, nurse)

When patients with a terminal illness are unable to move about and care for themselves and are therefore dependent on the help of others, there is a high risk of violation of their integrity and identity as a human being (Nordenfelt, 2004). For instance, Albert expressed how the loss of bodily control and competence had a profound impact on his wife's sense of dignity and, at the beginning, it was very difficult for her to accept being dependent on others:

“It has an impact because she can't stand alone. She can't go to the bathroom. She has to use diapers. She can't care for herself. Now I think she accepts this. But at the beginning it was very difficult for her.”

(Albert, husband)

This opinion was also expressed by Allison, who argued that dependency has challenged her husband's sense of dignity. She explicitly referred to her fear of being dependent like her husband. Allison left her work in order to help her husband when he became dependent on others for day-to-day activities. She also hired a nurse to help her with her husband's care. When he was admitted to the palliative care facility, she decided to move to her daughter's house so she could visit him every day. Allison perceived her husband's dependency as a greater problem:

“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 for anything, a person who has to call someone for their basic needs. I am wondering if that's dignity.”

(Allison, wife)

When asked to describe what threaten his sense of dignity, Ben explicitly referred to the loss of his ability to work. He had lost his wife, his parents had also died and he had no relatives, so for him work was the only goal in life. Because of his illness he suffered from fatigue and, for this reason, was forced to leave his work. He expressed negative feelings about his limited action and said he wished to return to a more active life:



“Interviewee: “I’m not saying that I’m an invalid. Because I don’t have the capacity to analyse this. But I feel I’m half-dead.

Interviewer: Why do you feel you are half-dead?

Interviewee: Because of the disability that I have nowadays. If I have the chance to work I am sure I will forget this immediately. The reaction will be different. I could gain more inner strength.”

(Ben, dying patient)

What this respondent is claiming is that his loss of ability to work has had an impact on his sense of ‘self’. A similar observation was made by Charmaz (1995) who, in her study on the nature of the suffering of the chronically ill, argued that when these sufferers were forced to abandon their work they ended up to being marginalised, leaving their existing social worlds and thus experiencing a deterioration in their self-image. It is interesting to see that, because men are trained for a world of action (Franzoi, 1995), when they lose the ability to perform tasks by themselves they are likely feel that their life has lost any positive value (Lawton, 2000). In addition to the loss of bodily autonomy, a few patients spoke about the aesthetical aspects of their body and the ways in which the illness had had an impact on it and therefore on their sense of dignity. Becky explained:

“Interviewee: I think I have lost my dignity.

Interviewer: Why?

Interviewee: Because I can’t do anything. I can’t dress myself. I can’t buy clothes. It was something I enjoyed doing. For example, going to the sales. Seeing the sales. Not to buy but to see the sales. This has ceased to exist. So I think I have a fictional life.

Interviewer: Do you think your life is fictional because you can’t do things on your own?

Interviewee: I can’t do useful or futile things. Because obviously going to the sales was futile. Anyway, I have lost all this.”

(Becky, dying patient)

What both these respondents are demonstrating is that the ways in which terminally ill patients view their bodies vary according to gender. Whereas women are more likely to understand their bodies as discrete parts that are aesthetically evaluated by others, men are

more likely to perceive their bodies as a dynamic process where function is a more important consideration than beauty (Franzoi, 1995: 417). It is interesting to see that gender shapes body ideals. These respondents' insightful statements reveal the corporeal foundation of selfhood (Merleau-Ponty, 1962). Indeed the respondents underlined the existential expressiveness of the body and its relation with selfhood (Kontos, 2004).

Thus, our findings show that the deterioration of the body, as the physical expression of 'self', and the lack of self-containment due to the progression of a disease are likely to influence the meaning and experience of dignity for people facing a terminal illness. It is interesting that this individualistic discourse on dignity was expressed by almost all terminally ill patients and their family members interviewed for our study. In contrast, a large part of the palliative care staff indicated that dignity was deeply interwoven with a holistic notion of the human being. Nordenfelt (2009) has used the German word *Menschenwürde* to describe it. This is often translated as human dignity and is defined as the dignity that all individuals have, equally, by virtue of their being human. Capri, who had a strong Catholic background, stated:

“Someone has dignity 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 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 assistant)

This statement clearly shows that dignity may be related with respect for human rights. According to Nordenfelt (2004), because human dignity refers to a kind of dignity that all individuals have by virtue of being human, no one can be treated with more or less respect, regardless of basic human rights. The ideal of human dignity was explicitly referred to by Carl:

“It's to give meaning as a person. Making them feel that they are a person. That they have a value as a person. That their life has had a meaning. That their life still has a meaning despite their condition.”

(Carl, nurse)

What this respondent is claiming is that terminally ill patients should be valued for their worth as a person (Jacobson, 2007). It is interesting that there was a moral obligation of respect (Nordendelt, 2009) from staff members for the uniqueness of terminally ill patients (Jacelon and Henneman, 2004), as indicated by Chantal:

“Dignity from my point of view is to be treated as I have always been. Not to be seen as less capable. As less useful. As less important. As less valuable. Because I am in a certain situation. For me this is dignity. It is the respect that others have for me. For my autonomy. For my individuality. For my tastes. For my beliefs. For my culture.”

(Chantal, psychologist)

Dignity was experienced as an attribute of the self and made apparent through the respectful behaviour of others (Jacelon et al, 2004). This is how Candy explicitly referred to the importance that meeting patients’ needs and wishes has in the meaning and definition of dignity:

“I think dignity is to be able to meet patients’ wishes. In terms of their psychological, physical and spiritual needs. I think their wishes are central. This represents dignity.”

(Candy, psychologist)

What this respondent is saying is that terminally ill patients should be treated as whole persons, with physical, social, psychological and spiritual needs (Chochinov, 2006). Thus, our findings reveal that this holistic narrative on dignity is very much embedded within the philosophy and practice of hospice and palliative care, namely within the notion of total care. Drawing upon the notion of total care, suffering is defined as a physical, psychological, social and spiritual experience (Clark, 1999). In order to enhance a patient’s dignity in the dying process the physical, psychological, social and spiritual dimensions should be addressed by palliative care professionals (Clark and Seymour, 1999). This may be understood as a way of ‘humanising’ the care given to terminally ill patients in palliative care (Lawton, 2000). Having outlined the patient-centred and holistic approach to such care, we shall now turn to a more detailed consideration of the philosophy and practice of the care given to terminally ill patients.

## **The ideal of dignified care**

Although in the previous section we acknowledged the person-centred and holistic ideal advocated by the proponents of the modern hospice and palliative care movement, other important topics emerged in our study pertaining to the practice of the care given to terminally ill patients. Interestingly, when asked to describe the hierarchy of care that informs this practice, almost all staff members explicitly referred to the importance given to the management of pain and physical discomfort. A similar observation was made by McNamara (2004) who, in her study on the ideology that informs palliative care, found that the staff gave prominence to the physical care of patients and the medical responses to suffering and death. Indeed, in our interview, Capri, who was very keen on palliative care philosophy, spoke about a care hierarchy that prioritises pain and symptom control:

“The first thing here in palliative care, before the intervention of a psychologist, a psychiatrist, a physiotherapist or myself, is to control the pain and the symptoms, because we can only work on other aspects after this. There are people who have come here in a really bad condition, without pain control and with extreme physical suffering. Only after this is controlled we can work on other aspects.”

(Capri, spiritual and religious assistant)

This respondent’s perspicacious suggestion is that, without good pain relief, terminally ill patients are not able to embark on the journey of psychologically preparing their own death (McNamara, 2004). This issue was also indicated by Clara, who argued that pain and physical discomfort prompted by the illness exacerbate the patient’s wish to die earlier. She stressed that good pain relief and symptom control contribute positively to the comfort and care of terminally ill patients:

“If the symptoms are not controlled, I am sure that the person will think: I’m not doing anything here, it is better to die, I don’t want to live. This is true because the physical and psychological suffering will make the person not wish to continue – want to stop the process. I’m sick, I want to die. I’m not doing anything here. Living like this, it’s not worth it. If we can control the symptoms, the person is likely to feel better. The person sees that, despite having a chronic or terminal illness that affects their life, not being at home and not living their daily routines as

they would like to, they can have a day-to-day routine that is stable and happy in certain aspects. They will spend their days and hours differently.”

(Clara, nurse)

In addition to the staff members’ accounts, almost all terminally ill patients and family members interviewed for our study highlighted the importance of the control of pain and physical discomfort. For example, April expressed concern about the relief of her mother’s physical suffering. She indicated that she had had difficulty controlling her mother’s pain when she was at home because she would not take her medicines. She stressed that staff members made an effort to control the pain and symptoms prompted by her mother’s illness:

“Interviewer: Is the control of pain and symptoms something important to you?

Interviewee: Yes, sure. If not, she would be at home. If the staff have difficulty 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 has accepted it. She accepted it for her own comfort.”

(April, daughter)

This respondent was stressing that, although terminally ill patients experienced pain and other symptoms, there was a considerable effort by palliative care staff to minimize the physical discomfort caused by their illness. McNamara (2004) argued that the medical approaches to pain and symptom management are more likely to offer a sure and routine response to the dying process than the psychosocial elements of care. In addition, Clark (1999) claimed that freedom from pain appeared to provide access to the social, spiritual and psychological dimensions. This finding became apparent in our study. Carl, who had worked in palliative care since his graduation three years before, stressed that without symptom control the staff were not able to work on the psychological, spiritual and social dimensions:

“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 things but symptom control is the most important part of palliative care. It is extremely 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)

Although a large part of the palliative care staff highlighted the importance of the psychological, social and spiritual dimensions of care, our findings revealed that the hierarchy of care was likely to give prominence to the physical aspects. In the palliative care context in which our study was conducted the routines and practices of care were extremely well organized. Baths and bed-making were carried out in the morning. Meals were served at specific times. Drugs were given according to the doctor’s prescription at set times. The nurses and auxiliaries’ timetables were made according to the care routines and practices. This finding is consistent with the literature on the organization of hospice care. James (1992) found that the demands of physical labour have an impact on the hospice commitment of total care. Indeed, the mundane tasks related to daily living requirements such as eating and hygiene were given priority by hospice staff.

Furthermore, McNamara (2004) noted that the physical tasks were likely to be seen by palliative care staff as more predictable and easier to control. Hence, it could be argued that the nurses and auxiliaries were better trained to deal with the physical realities of dying than the emotional aspects related with a person’s death. In this sense, the hierarchy of palliative care can be seen as a product of the medical gaze (Clark, 1999) since it conforms to the biomedical model, which gives prominence to the objective body (McNamara, 2001). Costello (2001) also pointed out that, though nurses acknowledged the importance of psychological care, they tended to give priority to the provision of physical care. An interesting point made by Costello is that nursing care usually takes place within a professional culture based on a curative ideology. So the emphasis is placed on treatment and cure rather than palliation. Indeed, our findings revealed that more than half the members of the nursing staff in both units also worked in acute hospitals. Therefore, it appeared that this personal context was likely to inform the practice of palliative care.

A few interview respondents claimed that the physical aspects of care were likely to have an impact upon the sense of dignity of terminally ill patients. Indeed, without adequate provision of food and hygiene people facing a terminal illness feel less worthy of respect and esteem. For instance, in response to a question about the importance of the physical aspects of

care, Cecilia indicated that respect for the dignity of those who are very ill and at the end of life is a central aspect of palliative care:

“I think it is extremely important. If we think about how we will feel if someone is caring for us, we can understand the way this is important. Firstly, in terms of their identity and in terms of their privacy, it is very important. The fact is that, because of their body-image and self-esteem, some people need more physical care than others. But regardless of their needs, the intervention of the team is always the same. It’s based on the individuality of each patient. So we try to ensure that, as far as possible, certain aspects like privacy, autonomy and respect for dignity are kept in mind when they are cared for. This is the philosophy of the team. That is, to respect the privacy and identity of the other person.”

(Cecilia, nurse)

This respondent is clearly aware that in order to provide the best palliative care to patients the vulnerabilities prompted by their terminal illness must be taken into account. Thus, in addition to the physical labour, the emotional components of care were also highlighted by a large part of our interview respondents. Chantal explained this:

“The emotional components of care are also very important. The emotional components and physical components of care are closely interwoven.”

(Chantal, psychologist)

What this respondent is saying is that there is a strong relationship between the emotional components and physical components of the care given to terminally ill patients. It is interesting that moments of intimacy such as bath-times were seen by trained and auxiliary nurses as opportunities to explore the feelings of terminally ill patients. A similar observation was made by James (1989) who, in his study on the regulation of emotions, found that the emotional labour involved in care was likely to take place at intimate moments. For example, Ciara explicitly mentioned that the provision of bodily care was understood by staff members as a key opportunity to establish a close relationship with a patient and thereby enhance the palliative care overall:

“The physical care ends up being a key moment that we have with these patients. We can apply this to all care units. But, especially here, there are certain benefits from physical care. We can try to establish a relationship with the patient in a more holistic way.”

(Ciara, nurse)

This finding echoes previous studies on the use of emotions within the public domain. Drawing upon Hochschild’s work (1983) on emotional labour, James (1992) argued that the regulation of emotions was central to the good organisation of the care given to patients in hospices. In addition, Rodriquez (2001) claimed that through the regulation of emotions palliative care staff were able to generate compliance on the part of terminally ill patients. In the case mentioned above, April was very concerned with her mother’s behaviour when she was admitted to the palliative care facility because she refused to take her medication. But the daughter indicated that she was very happy with the palliative care staff because they had worked on her mother’s feelings and changed her behaviour:

“I think they are exceptional because it is very difficult to get someone to come and have a conversation with her. But they are doing this. This shows that people here have the ability to do their work properly. That is, to make her calm down and be more cooperative.”

(April, daughter)

Emotions were used by staff members as a resource to help patients adjust to life in the in-patient unit (see Rodriquez, 2011), as Capri reported when telling a story about a patient who changed her behaviour after a conversation with some members of the palliative care staff:

“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 a 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 to feel a person.”

(Capri, spiritual and religious assistant)



The particular insight demonstrated by this respondent was that the members of the palliative care staff more often than not helped terminally ill patients maintain their self-control. Strauss et al (1985) called this composure work, which was seen as the work done by staff members to help patients keep their composure. Our findings reveal that emotions were used by palliative care staff, on the one hand, to generate the patients' compliance and, on the other hand, to enhance the patients' dignity (Rodriquez, 2011). Through the establishment of emotional ties staff members were able to maintain the dignity of those who were very ill and at the end of life since it provided these vulnerable people with opportunities to feel worthy of respect and esteem by others (ibid). Indeed, a large part of our interview respondents explicitly mentioned that they appreciated the caring relationships between staff members and patients. For example, Alan, whose wife suffered from mutism before her admission to the palliative care facility, stressed that he was very happy with the care given by the palliative care staff and that this had helped his wife:

“I think this kind of care is very good for the person. The person feels good, feels satisfied. She gives a smile, something that I haven't seen in a long time. When the nurses come to her room and ask her how she is, if she is well, if she has eaten, if she wants to eat in the bedroom, if she wants to eat in the dining room, if she wants to change her position, in a caring and affectionate way, with kisses and hugs, she feels extremely well. She expresses her gratitude with her look and her smile.”

(Alan, husband)

What this respondent is clearly demonstrating is that the relational character of emotions is not only useful for the palliative care staff but also for the terminally ill patients (Rodriquez, 2011). For this reason, the ideology of family care, which is part and parcel of the philosophy and practice of palliative care, and thus promotes familiarity and closeness (James, 1992), may be understood as a strategy of a sympathetic relationship (McIntyre, 2003). Karner (1998) claimed that a realm of privacy and intimacy may be maintained through the construction of a family relationship between the care recipient and provider. A similar observation was made by Dodson and Zinavage (2007) who, in their study of long-term facilities, noted that the ideology of family care was evident in the discourses of managers and workers in nursing homes when they were asked about the best way to provide compassionate care to their vulnerable residents. Indeed, Carla stressed the construction of a

fictive kin relationship between palliative care staff, terminally ill patients and family members, in this way:

“We are professionals, but people say, and I also feel this, that in a way this is a familial environment. In a way this a familial environment in which we can be with the family and the patient. There is always this relationship.”

(Carla, nurse)

In addition, Clara spoke about the way in which the establishment of close ties between the palliative care staff and terminally ill patients was likely to support the family ideology:

“There is a gain in confidence, without any doubt. They know us, we know them. Indeed there is a gain in confidence. They end up feeling more comfortable with us. Thus, it becomes a more familial environment.”

(Clara, nurse)

What these respondent are saying is that the family metaphor is often employed to give meaning to the hierarchical relationship established between terminally ill patients, family members and palliative care professionals (Lawton, 2000). Hockey and James (1993: 16) demonstrated that the family may be understood as a site within which relations of inequality and power are reproduced on an ideological level. Whereas the doctor may be seen as a father or mother, fellow patients may be viewed as brothers or sisters. For instance, a few patients referred to one another as kindred spirits. Ben and Bob said that because they spent a considerable time together they felt less lonely. Bailey and Becky also mentioned that their friendship had helped them deal with their illnesses. Thus, our findings reveal that the family metaphor offered patients an opportunity to feel normal and return to a normal life (Lawton, 2000). This was indicated by Charlie:

“Terminally ill patients end up seeing professionals as part of their lives at this particular moment in their lives. We celebrate their birthdays. We celebrate important moments in their lives.”

(Charlie, spiritual and religious assistant)

This respondent showed that the ideology of family care was employed by members of the palliative care staff as a means of personalising the care given to terminally ill patients and their family members (Lawton, 2000). It is interesting to note that, on the one hand, the family metaphor may be used by palliative care staff to establish a hierarchical relationship and gain patients' compliance, while, on the other hand, it may help patients to preserve certain aspects of their self-identity. In this sense, the care encounter may be seen as a place within which terminally ill patients may be able to create meaningful relationships with others (Wiersma and Dupuis, 2010). Thus, our findings show that through a sympathetic relationship palliative care staff may be able to enhance the sense of dignity of terminally ill patients (McIntyre, 2003). Dignity has been described as a core value, one that shapes the delivery of palliative care to terminally ill patients and their family members (Chochinov, 2006). For dignity to be maintained palliative care staff should understand patients as whole persons who deserve the respect and esteem of others (Chochinov et al, 2002). While palliative care offers a holistic approach and aims to palliate symptoms, mainstream medicine seeks to treat diseases and not the patients themselves (McNamara et al, 2004). Indeed, some interview respondents suggested that there was a contrast between the quality of the care given to patients in the palliative care facilities where our study was conducted and that given to them in general hospitals. Terminally ill patients and their family members have spoken about their traumatic experiences in terms of the care given in hospitals. For example, Albert stressed that it was very painful for him to see his wife tied to a hospital bed:

“At the hospital they did what they could but... I don't know... When I arrived there I saw her tied to the bed. When I arrived I untied her. They said that she was taking out the wires. Naturally, yes. I didn't question this. But it was a shock. It was a shock for me. Not only for me, for her too. She said: I'm tied here! I cannot move! I cannot scratch myself! I cannot do anything! Then she was tied all night.”

(Albert, husband)

Similarly, Beatrice, Albert's wife, indicated that she was mistreated by hospital staff:

“Interviewer: Have you felt any lack of consideration because you are sick? For example, in hospital?”

Interviewee: Yes, I think so. I think I was mistreated.

Interviewer: Why?

Interviewee: Because they didn't treat me as they should.

Interviewer: Can you give me examples of situations?

Interviewee: You asked me to give you examples?

Interviewer: Yes, of situations that have bothered you.

Interviewee: I cannot give you big examples because I was not lucid.

Interviewer: But who told you that?

Interviewee: I think it was horrible. My sister told me.

Interviewer: What did she tell you?

Interviewee: She said that they gave me tranquillizers. It was wrong because I had diarrhoea. So I couldn't take tranquillizers. I should have taken pills to normalize it.”

(Beatrice, dying patient)

Both these respondents suggested that the invasive and inappropriate treatments by mainstream medicine undermined the care given to terminally ill patients in hospital (McNamara et al, 1994). Indeed, these accounts clearly show that Beatrice's quality of life was compromised by the medical imperative to cure. In contrast, the experience of palliative care was not seen by terminally ill patients and their relatives as a traumatic experience but, rather, a very positive one. For instance, Angela explicitly mentioned that the palliative care was much better than that given in hospital. She argued that palliative care helps people die free of pain:

“Interviewee: I have no doubt! This is marvellous! It's much better than the hospital! But all the same it's very sad because I think this is the antechamber of death.

Interviewer: Why you say that?

Interviewee: Because I think, when patients come here, they are already lost. There is nothing else to be done. That's why I call this the antechamber of death. Not for being bad. But because of the circumstances in which they are admitted. Do you agree?

Interviewer: I don't know. Although you say this is the antechamber of death, do you think the care provided here is positive?

Interviewee: Yes, it's positive. Because they help people die free of pain. That was what I wanted.”

(Angela, sister-in-law)

This finding echoes previous studies. Gallagher et al (2008) demonstrated that the attitudes and behaviours of others have an impact on the sense of dignity of vulnerable individuals. When asked to describe dignified care, Carmen indicated that it is the kind that is capable of meeting the needs and wishes of terminally ill patients:

“I think we need to respect the person. Evaluate their own needs. Their own interests. And, above all, respect people’s interest. I think it’s the best way to show that we give a person dignity.”

(Carmen, doctor)

In addition, Celeste expressed the need to treat patients with respect for their worth as a human being:

“Dignity is caring. We should always bear in mind that there is another person in front of us. We should never replace them. We should always bear in mind that they may not be listening to us, may not even answer us, but we have a duty to speak to them, to explain everything and not go against their wishes.”

(Celeste, social worker)

These statements are very interesting as they show that, to provide dignified care, staff members should offer patients an individualized approach that recognizes their uniqueness (Nordenfelt, 2009). Tadd (2006) demonstrated that ensuring privacy, asking permission and providing information were important factors in maintaining the sense of dignity of vulnerable individuals. Andy illustrated this issue well in the following comment:

“Her intimacy is preserved wherever possible. Clearly she is restricted. So someone has to wash her. Someone has to clean her private parts. At these times they close the bedroom door. These are times to respect a person’s dignity. They have made an effort to maintain her dignity despite her limitations.”

(Andy, husband)

This respondent’s insight is that privacy boundaries play an important role in the maintenance of the dignity of patients with terminal illnesses. Chochinov et al (2002) observed that the patients’ sense of dignity can be influenced by feelings of having their personal space invaded during the provision of intimate care. For example, Aaron explicitly

mentioned that his father had not lost his dignity because of the efforts made by staff members to preserve his sense of privacy:

“I think my father has kept his dignity intact up to now. For certain concerns that he has in terms of his intimate parts. In a place like this I think his dignity has not been lost. He is not exposed. Those who care for him are very well prepared. My wife and my son have been very careful and left the room so he would not be shocked. So I don’t think my father is losing his dignity.”

(Aaron, son)

Thus, it appears that the ideal of dignity informs the care given to terminally ill patients. Palliative care aims to provide holistic person-centred care (McNamara et al, 1994) and, therefore, recognizes the importance of enhancing the dignity of those who are very ill and at the end of life (McIntyre, 2003). Carl spoke about the importance of the ideal of dignity to palliative care practice and in doing so stressed that palliative care staff need to show terminally ill patients that they still have their value as human beings. Although we acknowledged the institutional nature of the palliative care facilities where our study was conducted, our findings revealed that there was a considerable effort on the part of the palliative care staff to enhance the dignity of terminally ill patients. In sum, this section hopes to have demonstrated that through the ideal of dignified care terminally ill patients have the chance to feel their uniqueness as people until the last moments of their life.

## **Final Remarks**

This study aimed to provide a sociological understanding of the extent to which the dignity of terminally ill patients is affected when they lose their ability to act as autonomous agents. Our findings reveal that in the Portuguese palliative care context there are two distinct narratives on dignity. Whereas terminally ill patients and family members were more likely to express an individualistic narrative on dignity, which relates dignity to the individual’s ability to act independently, the palliative care staff were more likely to indicate a holistic narrative on dignity, which understands dignity as something that all individuals have, equally, by virtue of being human. While the former highlights the contemporary Western value of the individual’s responsibility (Giddens, 1991) to care for him/herself (Seale et al, 1997), the

latter refers to the uniqueness of the individual (Nordenfelt, 2009) and in doing so draws attention to the holistic, person-centred care advocated by proponents of the modern hospice and to palliative care movement (Clark and Seymour, 1999).

Although almost all the members of the palliative care staff acknowledged the importance of the psychological, social and spiritual dimensions of the care given to terminally ill patients, our findings demonstrate that they often give priority to the medical responses to suffering and the physical aspects of care (McNamara, 2004). Furthermore, the provision of bodily care was seen by palliative care staff as a key moment to explore the feelings of those who are very ill and at the end of life (James, 1989). Through the regulation of emotions palliative care staff were able to generate a patient's compliance and at the same time enhance the patient's dignity (Rodriquez, 2011). Not surprisingly, the relational character of emotions was beneficial for palliative care staff as well as terminally ill patients (ibid). For example, the family metaphor was often employed by patients, relatives and staff members to describe the palliative care given. Nevertheless, our findings show that this masks a hierarchical relationship between those who suffer and those who care for them (Lawton, 2000). In addition, the ideology of family care offered terminally ill patients an opportunity to return to a normal life and preserve their sense of self (ibid).

What this study intends to demonstrate is that the palliative care staff engage in a number of strategies to enhance the dignity of terminally ill patients and thus show them that they are still worthy of respect and esteem by others. Just because a person is dying and therefore has limited bodily autonomy, it does not mean that they are no longer a person. Instead, it is because a person is dying that we need to pay attention to their special vulnerability.

## References

- 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, 355-375.
- Chochinov, H.M., Hack, T., McClement, S., Kristjanson, L. and Harlos, M. (2002) Dignity in the terminally ill: a developing empirical model, *Social Science and Medicine*, 54, 433-443.
- Chochinov, H.M. (2006) Dying, dignity, and new horizons in palliative end-of-life care, *A Cancer Journal for Clinicians*, 56, 84-103.
- Clark, D. (1999) Total pain, disciplinary power and the body in the work of Cicely Saunders, 1958-1967, *Social Science and Medicine*, 49, 727-736.
- Clark, D. and Seymour, J. (1999) *Reflections on Palliative Care*. Buckingham: Open University Press.
- 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, 59-68.
- Dodson, L. and Zincavage, R. (2007) It's like a family: caring labour, exploitation, and race in nursing homes, *Gender and Society*, 21, 6, 905-928.
- Elliott, J.A. and Olver, I.N. (2008) Dying cancer patients talk about euthanasia, *Social Science and Medicine*, 67, 647-656.
- Franzoi, S. (1995) The body-as-object versus the body-as-process. Gender differences and gender considerations, *Sex Roles*, 33, 5/6, 417-437.
- 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 on 19 July 2010 <http://www.biomedcentral.com/1472-6955/7/11>
- Giddens, A. (1991) *Modernity and self-identity*. Cambridge: Polity Press.
- Hockey, J. and James, A. (1993) *Growing Up and Growing Old: Ageing and Dependency in the Life Course*. London: Sage.
- Hochschild, A. (1983) *The Managed Heart: Commercialization of Human Feeling*. Berkeley, CA: University of California Press.
- Jacelon, C. and Henneman, E. (2004) Profiles in dignity: perspectives on nursing and critically ill older adults, *Critical Care Nurse*, 24, 30-35.
- 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, 76-83.



- Jacobson, N. (2007) Dignity and health: a review, *Social Science and Medicine*, 64, 292-302.
- James, N. (1989) Emotional Labour: Skill and Work in the Social Regulation of Feelings, *The Sociological Review*, 37, 1, 15-42.
- Karner, T. (1998) Professional caring homecare workers as fictive kin, *Journal of Aging Studies*, 12, 69-82.
- Kontos, P.C. (2004) Ethnographic reflections on selfhood, embodiment and Alzheimer's disease, *Ageing and Society*, 24, 829-849.
- Lawton, J. (2000) *The Dying Process: Patients' Experiences of Palliative Care*. London: Routledge.
- McIntyre, M. (2003) Dignity in dementia: person-centred care in community, *Journal of Aging Studies*, 17, 473-484.
- McNamara, B., Waddell, C. and Colvin, M. (1994) The institutionalization of the Good Death, *Social Science and Medicine*, 39, 11, 1501-1508.
- McNamara, B. (2004) Good enough death: autonomy and choice in Australian palliative care, *Social Science and Medicine*, 58, 929-938.
- McNamara, B. (2001) *Fragile Lives: death, dying and care*. Buckingham: Open University Press.
- Merleau-Ponty, M. (1962) *The Phenomenology of Perception*. London: Routledge.
- Nordenfelt, L. (2004) The varieties of dignity, *Health Care Analysis*, 12, 69-81.
- Nordenfelt, L. (2009) *Dignity in Care for Older People*. Oxford, Blackwell Publishing.
- Rodriquez, J. (2011) It's a dignity thing: Nursing home care workers' use of emotions, *Sociological Forum*, 26, 2, 265-286.
- Street, A.F. and Kissane, D.W. (2001) Discourses of the body in euthanasia: symptomatic, dependent, shameful and temporal, *Nursing Inquiry*, 8, 3, 162-172.
- Seale, C., Addington-Hall, J. and McCarthy, M. (1997) Awareness of dying: prevalence, causes and consequences, *Social Science and Medicine*, 45, 3, 477-484.
- Strauss, A., Fagerhaugh, S., Suczek, B., Wiener, C. (1985) *Social Organization of Medical Work*. Chicago: University of Chicago Press.
- Tadd, W. (2006) Dignity and older Europeans, Cardiff Centre for Ethics, Law and Society, viewed on 19 July 2010  
<http://www.ccels.cf.ac.uk/archives/publications/2006/taddpaper.pdf>
- Wiersma, E. and Dupuis, S. (2010) Becoming institutional bodies: socialization into a long-term care home, *Journal of Aging Studies*, 24, 278-291.