Family Caregivers’ Social Representations of Death in a Palliative Care Context

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Abstract
The objective of this study was to consider the social representations of death of family caregivers in a palliative care context. The authors focused on the analysis of 23 interviews with family caregivers who cared for a terminally ill person at home and/or in a specialized palliative care unit, in Québec, Canada. The finding showed that family caregivers had different images that specifically represented death: (a) losses as different kinds of “deaths,” (b) palliative care as a place to negotiate with death, and (c) last times as confirmation of the end. These images highlight the meaning attributed to the body and the position of the dying person in our Western society. Representations of palliative care reveal a kind of paradox, a place of respect and of “gentle death,” and a place where death is almost too omnipresent. They also show the strong beliefs surrounding the use of painkillers at the end of life. Finally, these images refer to end-of-life personal rituals viewed as support for the passage into a new state of being. This study provides a better understanding of the common sense of death for family caregivers in a palliative care context and of the meanings of this emotional subject.

Keywords
social representations, death, family caregiver, palliative care, end-of-life

In modern Western society, people’s feelings about death are complex. In 1915, Freud said that nobody believes in their own death and human beings avoid broaching the subject with someone nearing death. However, death is the oldest reality shared by all of humankind and is the only thing of which all humans can be certain. Many thinkers have considered the evolution of representations of death throughout time, as seen in the work of Gorer (1955), Morin (1970), Ariès (1975), Thomas (1975), Vovelle (1983), and others in the past decades. Attitudes to death have profoundly changed in the last centuries, as have the associated social representations—cultural productions that facilitate our comprehension of social phenomena (Ariès, 1975; Kellehear, 2007; Morin, 1970). Morin (1970) referred to it as the crisis of death. According to Ariès (1975), from the Middle Ages to the first half of the 19th century, people were on more familiar terms with death and dying. There was a collective notion of destiny in which death was accepted as part of life. The dying process was a public event in which family, friends, neighbors, and children would gather and everyone knew their role. Death was seen as a biological phenomenon manifested by a series of natural signals known by the dying (Ariès, 1975). Death occurred when there was a complete and irrevocable cessation of vital functions. It was God’s will (Ariès, 1975) and the soul became immortal (Morin, 1970). However, the combined impact of medical advances, the decline of religion, the affirmation of the individual, and the value placed on individual autonomy have dramatically altered our relationship with death (Ariès, 1975; Larouche, 1991). There is an urgent desire to defeat death and disease, which is thought to be evidence of the failure of Western medicine to maintain youth and health (Clavandier, 2009; Hintermeyer, 2010).

These changes are also evident in the process of dying. In today’s society, death usually takes place in care institutions (Statistique Canada, 2012; Timmermans, 2005), even when the person has lived at home throughout the course of his or her illness. Biomedical practices shape our understanding of the parameters of death (Kaufman & Morgan, 2005) and how we recognize the end of life (Glaser, Strauss, & Anselm, 1966; Mino, 2013; Sudnow, 1967). Death is no longer the inevitable consequence of illness and old age, but the result of a series of medical decisions (Kaufman, 2000; Zimmermann, 2007). The integration of religion into activities of daily life also influenced attitudes and representations of death. The dying would place themselves in God’s hands. For the family, death was God’s will (Ariès, 1975) and the soul became immortal (Morin, 1970). However, the combined impact of medical advances, the decline of religion, the affirmation of the individual, and the value placed on individual autonomy have dramatically altered our relationship with death (Ariès, 1975; Larouche, 1991). There is an urgent desire to defeat death and disease, which is thought to be evidence of the failure of Western medicine to maintain youth and health (Clavandier, 2009; Hintermeyer, 2010).

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process unfolds in stages, sometimes making it difficult to recognize death when it actually comes, with the loss of consciousness or the cessation of vital functions (Clavandier, 2009).

Death and medical assistance for the dying are important concerns in contemporary social and political spheres, as shown by a recent public consultation on Bill 52 in Québec, Canada, held by the Select Committee on Dying with Dignity (2012), which resulted in passage of the Act Respecting End-of-Life Care in June 2014 (scheduled to come into force in December 2015). The right to receive palliative care and medical aid in dying is the central theme of this legislation.

Today, family members who care for a loved one are generally known as “family caregivers,” a concept developed in recent decades within a specific context. The concept became entrenched in the wake of the “ambulatory shift” reform, medical advances, increased life expectancy, and the existence of chronic illnesses that vested the family caregiver with a new level of responsibility for a sick loved one that can extend over many years, until the person’s death (Wierzbowski, 2008).

The palliative care approach emerged in the late 1960s, and diverse health institutions set up the practice of this new area of care (Hintermeyer, 2010). Palliative care has underlined the importance of easing pain and suffering in the dying process. For Rossi (2010), the palliative approach can be seen as a collective response to the fear of death. In relation to these observations, what are family caregivers’ social representations of death after the experience of accompanying a dying loved one in a palliative care context? The aim of this article is to explore the social representations of death of bereaved family caregivers.

Few studies have been done on the social representations of professionals (Bellavance, 2011; Bernard, 2009; Dany, Marie, & Salas, 2007; Dany, Rousset, Salas, Duffaud, & Favre, 2009; Maresca et al., 2004; Salas et al., 2008) and the experience of patients (Lawton, 2002) and the general public (D’Hérouville, 2010) with regard to palliative care, cancer, and the elderly in society (Cannone et al., 2004; Lalive d’Epinay, 1995; Marie, Dany, Cannone, Dudoit, & Duffaud, 2010). To our knowledge, no study has been undertaken on the specific social representations of death of family caregivers in a palliative care context. Considering the literature, we think this study is particularly relevant to two fields of interest. First, from a scientific perspective, the study of social representations can help provide a better understanding of the common sense of death for family caregivers in a palliative care context. Second, trying to understand different meanings can help to improve the practices of professionals who care for dying patients. Death is an emotional subject; it generates emotional reactions that can affect behavior and the mourning process.

The Concept of Social Representations

Often used in social sciences, social representations refer to a variety of meanings, boundaries, and definitions (Mannoni, 2010). They are defined as an organized structure of beliefs, opinions, attitudes, images, and information constructed around a specific object (Abric, 2003; Jodelet, 1989; Seca, 2010), which help humans understand the world, and guide actions and behaviors (Mannoni, 2010). They are an instrument of communication. Representations are part of an individual’s universe and are constructed through interaction with others (Bellavance, 2011). As reported by Doise (Doise & Palmonari, 1986) and Mannoni (Mannoni, 2010), images associated with meaning are aspects of social representations. Each image is linked to a meaning, and each meaning is linked to an image. Their function is to transform an unusual phenomenon into a familiar one (Jodelet, 1989). They help to explain reality (Doise & Palmonari, 1986; Jodelet, 1989; Moscovici, 1989). According to Seca (2010), representations take form and grow in daily conversation and are associated with specific situations. The relationship to others and to the world is then modified (Jodelet, 1989). Social representations are studied to learn a group’s common sense of a specific context. The representations of death in palliative care generate images. The core elements of these representations generate the most commonly expressed images (Moliner, 2008). They are commonly used to describe and understand their inherent meanings. They are essential to understanding emotionally charged topics such as death and palliative care (Bellavance, 2011).

Materials and Method

The data used for this article were initially gathered for an earlier study (forthcoming) conducted in an integrated university health and social services center (CIUSSS) in the north of Montréal to assess the needs of family caregivers and services provided to end-of-life patients in palliative care. Family caregivers spoke spontaneously about their experiences, evoking powerful images of what death represented for them. We decided to proceed with a secondary analysis of the data to explore the social representations of death after the experience of accompanying a dying loved one in a palliative care context. The initial study used a mixed-methods design that drew on data from different sources (family caregivers and professionals, semi-structured interviews, a cross-sectional survey, and medical databases) but, for the purpose of this study, we focused only on an analysis of 23 interviews with family caregivers who had cared for a terminally ill person at home and/or in a specialized palliative care unit (only one person died at home).

Caregivers were initially selected according to the following criteria: (a) has benefited from palliative care services at home and/or in the specialized palliative care unit in the territory of the CIUSSS, (b) is the principal caregiver in the patient’s medical records, (c) has taken care of the terminally ill person in the last 3 to 6 months, and (d) is willing to participate in a face-to-face interview. The first authors contacted them by phone before meeting with them. Eighteen women and five men participated between December 2012 and February 2013: spouses (10), children (seven), sisters (four), niece (one), and son-in-law (one).
An open-ended interview guide was developed with several relevant sections: evolution of the disease, experience with care and death, experience with palliative care services, needs of caregivers, social and cultural aspects of support, both given and received, and interaction with the formal and informal network. The interviews were conducted by a research officer and anthropologist (first author), at the caregiver’s chosen location—home, café, or a private room in the CIUSSS. Interviews were done in French or English and lasted from 30 to 120 min (Lessard, Leclerc, & Mongeau, 2014). All interviews were recorded (with written consent) and transcribed.

The study was approved by the executive director of the institution and conducted in accordance with the provincial health and social services act and the ethical standards of the university institution (Leclerc et al., 2014; Ministère de la santé et des services sociaux [MSSS], 2007). Participants were clearly informed that their participation was voluntary and anonymity was preserved.

Data Analysis

We used a qualitative thematic analysis to enhance the understanding of the family caregivers’ social representations of death. Using QDAMiner Software, we examined the materials by breaking the interviews into small units of categories (Negura, 2006) focused on social representations of death (Vaismoradi, Turunen, & Bondas, 2013). As empirical studies on our subject are poorly documented, we used an inductive open manner to identify different images representing death. The thematic analysis provided us with an overview of the data within the specific context (Vaismoradi et al., 2013) of palliative care. The first author analyzed the content of each interview, and the other two authors validated the results in several consultation sessions. The images reported by interviewees emphasized the meaning of the social representations of death expressed by the family caregivers. Qualitative coding underlined family caregivers’ social representations of death and those of the person they cared for through the end-of-life process.

Results

The analysis of the interviews showed that family caregivers had different images that specifically represented death. The images are personal, but together, they reveal a common sense of death in the palliative care context. We grouped the images into three separate categories: (a) losses as different kinds of “deaths,” (b) palliative care unit as a place to negotiate with death, and (c) last times as confirmation of the end. These different images represent non-linear steps in the end-of-life process, but they were all lived in a palliative care context (Table 1).

| Losses as different kinds of “deaths” | Palliative care unit as a place to negotiate with death | Last times as confirmation of the end |
|--------------------------------------|---------------------------------------------------------|-------------------------------------|
| Failing bodies                       | Palliative care unit as the last home                   | Last time                           |
| Social death                         | Death comes wrapped in a white cloth                    | Death conversation                   |
| Vanishing quality of life            | The goodbye injection                                  | Call of death                        |
| Transformation of the loved one      |                                                         |                                     |
| Break in the bond of communication   |                                                         |                                     |

Losses as Different Kinds of “Deaths”

Family caregivers reported that the care process occurs over a period punctuated by major changes, all associated with losses. They happen at different points during the illness. Each of the following images was linked with death and was significant for the dying person and/or for the caregiver.

Failing bodies. The interviews show how the transformation of the physical body is associated with death. The family caregivers described the deterioration of the person’s physical condition. This was often a slow process, lasting from hours to months, depending on the type and stage of the disease, but with the constant awareness of the imminence of the ultimate loss. Disturbing images were associated with the deterioration of the body. A caregiver described her feelings about her sister when she realized she could not stand up anymore.

I found it difficult, when she was not able to get up anymore. She was bedridden and always asleep. I found it rough. It was the announcement of the beginning of the end. So it slaps you in the face.

A daughter explained one of the last mental images she had of her mother

Sometimes, I have this image in my head. The swollen chest, the mouth wide open and her despairing eyes. I had never seen eyes like this. And this, it hit me, the ears were glued to her head. That meant not a lot of time left to live.

Another woman mentioned that her mother compared her body with a puzzle falling apart:

In the morning, she told me, “It is true my daughter, it is today that I am leaving.” She told me: “it is as if my body was falling apart, it leaves me. It is like a puzzle.” At one point, she had two mouths, three stomachs. And she wasn’t on morphine.

The significance of these different images was clear for these women; the deterioration of the body was directly...
linked to the arrival of death. For some of them, these images will remain in their minds long after their loved one’s death.

**Social death.** Family caregivers described how their loved one suffered due to the loss of belongings or social status for which they had worked all their lives. Their exclusion was dual in nature, experienced in terms of their perception of themselves and the perception of others. The image of the loss of themselves was clearly associated with the end. At this point, they felt the loss of their social status. A spouse described how her husband’s physical condition affected his job:

> He had injuries around his nose . . . At that point, she (their boss) called me and told me: “I am sorry but I am obliged to tell you that you can’t come and do your show anymore because the residents are in shock from seeing Roger (her sick husband) in this condition.”

Another caregiver described her mother’s feelings about her belongings as she lived through the last stage of her life:

> That’s what she told me: “My daughter, I have no control over my life anymore. I have no car anymore, no house anymore, no more projects, I have nothing left except my head.” Her goal was to keep her mind as long as possible.

The image of dispossession is a strong one.

**Vanishing quality of life.** This image spoke to the relationship between quality of life and death. Many family caregivers spoke about this. For some people, the loss of quality of life meant acceptance of the dying process. Some of those who were dying had no hope their condition would improve and wanted the situation to stop. They associated it with their life coming to an end. Two daughters reported their respective mother’s speech near the end:

> When she had her heart attack, she shouldn’t . . . she wasn’t to go back home. Her quality of life was gone. She said to us “There is no quality of life for me, and there won’t be any in the future. I will go from one hospital to another.” At that point, she decided to stop everything (treatment).

She used to say: “I have no more quality of life, it is crap. I am no longer able to stand up anymore and to go pee by myself. I can’t live in such conditions” . . . She was sick, she had no more quality of life and it was her choice, she pushed to end it. She wasn’t scared.

**Transformation of the loved one.** When an ill person undergoes a major change in their behavior, this is evoked by the image of the transformation of the loved one. The behaviors induced by the end-of-life process deeply affected some family caregivers who felt they could barely recognize the “new” loved one. For one husband, he experienced his first real loss when he saw the transformation of his wife’s behavior. The person he used to know, at that point, was gone. “All her gentleness, she lost her gentleness . . . She was a really gentle and sweet person. She began to die before dying. And I couldn’t do anything. It was difficult.”

**Break in the bond of communication.** This representation occurred during the end-of-life process, and therefore, some family caregivers felt the real loss when their loved one went into a coma, before the person’s actual death. The image of a broken bond of communication represented the end. The loss of consciousness was viewed as the irretrievable end of communication with the loved one. A daughter described her sense of loss when she realized that her mother was about to lose her mind:

> I can say that the most difficult moment was when the link broke, when my mother said “my daughter, it is true, I am leaving.” And then, the relationship stopped with my mother. I found it so difficult not being able to communicate with her anymore.

**Palliative Care Unit as a Place to Negotiate With Death**

Interview respondents reported different representations of the palliative care unit, confirming the personal meaning of palliative care. For all of them, the palliative care unit was a place of great service, and at the same time, it represented the arrival of death. They referred to different images.

**Palliative care unit as the last home.** On one hand, family caregivers see palliative care services as a release from the responsibility of caring for their loved one. At the same time, it confirmed the reality of approaching death. The act of moving from home to the palliative care unit was experienced by family caregivers as a moment when they were confronted with the end. For many, the palliative care unit was seen as “the last home,” “the end.” A spouse expressed how she experienced the departure of her husband from their family home to the palliative care unit:

> I heard a lot about the palliative care unit. That it was really nice. When they arrive (ill person) at that stage, there is a kind of detachment . . . When he left in the ambulance, he knew he was not coming back, it was really emotional.

This departure was also experienced as a failure by some family caregivers, and the care unit seemed to represent a place of death. They judged themselves as having failed in caring for their relative. This was especially true when the stay in the unit was too short for them to appreciate the palliative approach offered by the professionals.

> I could have had some great moments. The only image I have left, is of my wife making a grimace while receiving a shot from
the nurse. It is the last vital sign I remember. She was at the palliative care unit for three days.

As mentioned above, the palliative care unit was associated with both attentive care and death. It was difficult for family caregivers to hide the end-of-life process from their loved one, especially when the subject had been avoided. The image of death remained engraved in the mind. A son explained how he dealt with hiding the situation from his father, because it was so strongly associated with death.

I pretended like palliative care was just like this but he knew what it meant, palliative care. “You, you won’t die. Forget it, the doctor only signed for you to get a room and look at the services you get.” He played the game with me. But at one point, there were people dying next to him . . . I found it rough.

*Death comes wrapped in a white cloth.* A strong image of death represented in palliative care is that of the dead wrapped in a white cloth. Family caregivers often expressed acceptance of the arrival of death. However, the analysis showed that seeing people dying in the palliative care unit confronted them directly with the reality. Many of the family caregivers mentioned the negative effect on their morale of knowing and seeing people dying close by. Death was too close. A daughter spoke of finding out that nine people died in one night at the palliative care unit. “There are 12 bedrooms, only three were still occupied. Over the night, nine . . . God, it gives you a slap in the face!” A husband stressed his discomfort with the fact that his wife was aware of the death of others around her:

There is only one thing that was hard. I don’t know if they can do something to improve the situation. When there is a new person who arrives (ill person in the palliative care unit), they should put them in a wing for people more in shape . . . Once, she (his wife) said hello to someone, and the day after, he was covered up dead. There were three who died during her stay . . . Once, she saw somebody who just died. The effect this had on her . . . two days later there was another. Whatever, I don’t know, I speak on her behalf even if she knew why she was there.

The *goodbye injection.* The interviews showed that palliative care was viewed as a way of dying without extreme physical suffering. “That’s why we lived at the palliative care unit, these were palliative care services because you feel and observe all the medical assistance for physical and physiological well-being.” “I can say that she did not suffer. At the unit, each time a professional saw her in pain, they gave her an injection.”

However, there was a strong representation shared by family caregivers of the “goodbye injection.” The painkiller injection was viewed as a medical act to ease pain and induce death, especially when the ill person fell into a semi-coma and then died. They reported having accepted medical care to relieve the pain, and some of them felt guilty after having accepted such care. Here are a few of the quotes expressed by different family caregivers. “The hardest moment was when I realized what I’d said yes for; the perfusion to relieve the psychological distress. It was the goodbye injection.”

The doctor gave his authorization to put her in a deep coma . . . I thought it was a natural process, that it was the natural evolution. “She has been getting shots,” everybody said. OK fine, stop telling me, now I know.

Other family caregivers mentioned witnessing the normal course of the dying process. They explained the necessity of the pain medication and its link with the dying process. “And then, they started to give morphine on Wednesday. The Friday around noon, he had his injection and he fell asleep. It was finished, he died at midnight.”

The injection, for others, seemed to be a way to shorten the dying process:

Until her last moment when she was able to communicate, especially the very last moment, she found it really long. She was looking forward to the end . . . My sister tried to influence the formal caregivers to increase the morphine doses or I don’t know what . . . even if she was ready to die, at one point, she didn’t have any control on her thoughts, her body strived. It wanted to stay, survival instinct.

*Last Times as Confirmation of the End*

The end-of-life process was reported to be associated with different ways of saying goodbye. Family caregivers spoke about their experiences with their relative while approaching the end. Their different actions or behaviors were a kind of ritual surrounding death, and they were linked to images.

*Last time.* Mostly, family caregivers reported having organized a last get-together for their loved one with family and friends. The event was a moment to say good things about the past and wishes for the future. It was a chance to give the sick person pleasure and see he or she had everything he or she wanted. Family caregivers experienced different last moments.

I knew how to please her for her birthday . . . party hat for the mother, big strawberry shortcake, she was happy. Because everybody knew it was her last birthday, she knew it as well. We took pictures and had cake.

For others, it was an opportunity to say goodbye

My mother used to call her people to say goodbye . . . She called her friends and told them, “I just want to say that I am at the hospital and that I am leaving. I wanted to say goodbye.”

A spouse explained how the ritual continued once her husband died as a way to accompany him. It was the first step in the memory of the living.
We put some candles in the bedroom and classic music that he used to like. My son-in-law got a bottle of wine and gave us a full glass and “cheers” . . . It was OK, it was a kind of closure.

**Death conversation.** The image of the death conversation was omnipresent in the interviews. Family caregivers reported that it was difficult to speak directly of death. They told us how uncomfortable they were about broaching the death conversation with their loved one. Many of them then felt sorry they had avoided the subject. We explored different ways of approaching the death conversation, for instance, to plan funerals and other logistical issues with the dying person.

We had made her will. We had the talk but she counted on me, it was to my discretion because she had difficulty talking about death. She was really scared . . . When we talked about death or that she knew that she was about to die, she used to get upset.

We also observed that some family caregivers saw the death conversation as an overly strong representation of death to the point it became a taboo subject. Some decided to take the opposite stance and evoke a positive vision of future health conditions. They said they did this to protect their loved one.

She was so scared to die. We did not . . . I did not talk about death with her. However, I tried to encourage her, to tell her that she would get better. She would feel better, maybe tomorrow she would feel better still. But . . . how long can we lie to try to change the patient’s vision? At one point, she couldn’t get up. So, it was just to say that we were there for her and that it was to be for the best.

Respondents also emphasized the difficulty of communicating with a dying person. One caregiver reported he retreated into silence while trying to talk with his wife. He did not know what to talk about with her. The past, the future, or everyday conversation was not an option for him. He adopted the silence of death.

In the last months, I was not able to talk anymore. Luckily, my sister-in-law was there to listen to her. Me, I was unable to do so. The kids used to tell me, “Talk to her, talk to her.” I told her, “I will always love you.” It was the only thing I had to say.

The same man mentioned in the interview how he would have liked professional accompaniment to face the difficult situation. For him, the death conversation would have been an important moment.

I learned something afterward. A friend of mine told me that when he was caring for his wife, they had access to a social worker. He (the social worker) talked with both of them, to the wife and to the husband. He made them ready for death. I think I would have loved to have that. It would have opened us up to talk about it. We didn’t talk about it at all.

**Call of death.** Finally, family caregivers reported how they experienced the arrival of death. Many of them knew it was coming as they observed their loved one feeling and seeing death approach. The sick person’s feelings were shared in different ways. A spouse described it like this:

The last day he was mentally with us, the Easter Saturday. He died the next Wednesday. During that day he began to say that his brother was coming. “Peter is coming, Peter is coming.” Peter was his brother, who passed away many years ago. So then, I knew that it was coming. When we begin to see dead people, it was because we are engaged in that path.

**Discussion**

Social representations on the subject of death have been abundant over the years, from historical (Arriès, 1975; Vovelle, 1983), sociological (Morin, 1970), and anthropological (Gorer, 1955; Thomas, 1975) perspectives. Based on empirical data, this study provides new knowledge about social representations of death in a palliative care context.

The article presents images spontaneously created by the caregivers themselves that illustrate their vision of death. Using a qualitative thematic analysis, we identified certain images and the common sense that was ascribed to them. In all, we came up with three main groups of typical images: (a) losses as different kinds of “deaths,” (b) palliative care unit as a place to negotiate with death, and (c) last times as a confirmation of the end.

It seemed appropriate to highlight the strongest images in social representations and to link them with the current social context. Our study distinguishes itself in two ways: the subjects that were studied (family caregivers) and the context of the study (palliative care). Both of these particularities are characteristic of our unique contemporary situation.

Images of loss such as the failing body, the social death, and vanishing quality of life refer directly to the end of existence and a person’s death even before the person’s physical death has occurred. These images highlight the meaning attributed to the body and the position of the dying person in contemporary society (Clavandier, 2009; Le Breton, 1992). As a social object, the body is a key element of our identity (Clarke, Griffin, & Team, 2008), acting as a mirror that conveys information about a person, and based on which others and the person herself or himself form judgments. The body is usually the focus of health, well-being, youth, and fitness that must be maintained. It is therefore not surprising that when the body of a sick person begins to deteriorate and their appearance transforms into something that contrasts with the ideals of health and beauty, the sick person feels excluded and family caregivers begin to evoke the approach of death. This social death (Lawton, 2002) occurring before the person’s physical death refers to the position of the dying person in our society, an ambiguous position because the sick person no longer really belongs to the category of the living, but neither is she or he in the category of the dead (Clavandier, 2009).
Our data revealed that powerful images are representing palliative care. They evoke a place permeated by respect and an approach focused on reducing the physical suffering caused by a life that is on the wane. The sick no longer die suffering intolerable pain. Palliative care may also, however, represent death; family caregivers described the image of the last place the loved one would live, and that of the dead person wrapped in a white cloth—the omnipresence of death around them. The palliative care unit is also the place where death is accelerated and where family caregivers mistook the soothing of pain through the administration of a painkiller (usually refers to morphine) with the “goodbye” injection. The possibility of hastening death may be strongly associated with the easing of suffering. This representation generates genuine confusion among family caregivers, and some felt responsible for the death of their loved one. The use of morphine and other medications to ease patients’ suffering can alter their consciousness. This explains the loss of consciousness or “deep coma” reported by some of the caregivers. However, the literature on the subject tells us that the administration of pain medication neither hastens nor delays death (Rurup, Borgsteede, van der Heide, van der Maas, & Onwuteaka-Philipsen, 2009; Rurup et al., 2010). This representation may also be explained by the extensive media coverage of the National Assembly of Québec’s public hearings on dying with dignity. Medical aid in dying, euthanasia, and assisted suicide have become the subject of a broad public debate among Quebeckers (Leclerc et al., 2014; Simard, 2013). In light of these results, representations of palliative care reveal a kind of paradox, a place of respect and a “gentle death,” and a place where death is almost too omnipresent.

Family caregivers also spoke of images they associated with end-of-life rituals such as the person’s last moments, the “death conversation,” and the “call of death.” Death is a defining moment, in which relational dynamics have a major impact, both on the person who is dying and on the bereaved and the grieving process. The findings of our analysis show that end-of-life rituals are individual and personal. They are conducted in private and most often only involve the family and immediate circle. This observation echoes a point recently raised in the literature: Despite the individualized practices that have replaced traditional rites, individuals still, and will always, turn to rites in these circumstances (Bussières, 2009; Clavandier, 2009). Rites can be viewed as support for the passage into a new state of being. They can also be seen as a means of dealing with the anguish of loss.

Various representations of death are associated with a rupture or change in the nature of communication with a loved one. The break in the bond of communication happens when the person goes into a coma or undergoes a behavior change, or when silence sets in because the caregiver sees no possibility of a future with his or her loved one. The comments of Le Breton (2004) concerning the imperative of communication in our era highlight the feelings of unease or anxiety felt by family caregivers when they can no longer communicate with the sick person approaching death. In light of Le Breton’s (1992) remarks, we might well consider whether this anxiety is not a product of Western society, which promotes and creates the expectation of dialogue in all phases of life. Some of the caregivers who participated in our study reported that their loved ones did not recognize their impending death although they were in a palliative care setting and their caregivers had been informed of the situation. Glaser and colleagues (1966) have described the mutual pretence as a “closed awareness” context. These caregivers believed that their loved ones did not wish to know they were dying.

We believe it is important to examine the usefulness of these representations for front-line practice and interventions. A consideration of the different social representations of death could give health practitioners a fuller understanding of the attitudes of family caregivers and the diverse logic underpinning their actions. In this respect, our findings have highlighted the operating logic of family caregivers as not necessarily exclusively rational, but also rooted in the symbolic, relational, and emotional registers. The findings underline the importance of continuing public information and education regarding the use of morphine. Some family caregivers associated the injection of morphine with the arrival of death, which caused them to feel guilt and frustration. The beliefs surrounding the use of morphine and other pain-relieving medication at the end of life are numerous and appear to persist over time despite public awareness activities by health care organizations. The numerous deaths that occur in palliative care units remind family caregivers of approaching death in a manner that is almost brutal. We believe it would be appropriate to consider whether the reactions to these deaths might serve as a lever for addressing anguish about death and fears about the future (Arnault, 2004). Last, the representations associated with ruptures of communication may be alleviated somewhat through professional support in the form of mediators or facilitators to help the family and their loved one (Arnault, 2004). When the person who is dying goes into a coma and the communicational bond appears to be broken, professionals can use this as an opportunity to encourage the family caregiver to communicate using other means than words.

This qualitative study is still exploratory in nature, and results cannot be generalized to other contexts, cultures, or eras. A qualitative study does not generally seek to extrapolate the findings to the population in general, but rather aims to further investigate and better understand the phenomenon under study. This research describes the social representations of a culturally homogenous group, in other words, most of the individuals interviewed were born in Canada. Considering the increasingly multicultural character of Montréal, and Québec in general, it is essential to consider, for further research, this subject with individuals of various backgrounds, beliefs, and cultures. Studies on family caregivers’ social representations of death in different contexts, such as long-term care facilities, could further contribute to our knowledge, given that all those who live in these centers spend their last moments of life there (Leclerc et al., 2014).
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