

Hospice Philosophy in Practice—Toward an Authentic Death

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Abstract

This article examines how hospice philosophy works in contemporary Danish hospice practice. The still sparse literature on Danish hospices indicates that hospice philosophy *is* influencing professional practice. In international palliative care literature, hospice philosophy is challenged for being overly normative *in its ideal of the good death* or on the other hand as threatened by the medical model. Drawing on the idea of hospice philosophy as providing meaning for everyday practice, this article explores how it is incorporated within the institutional order of contemporary Danish hospices. An ethnographic study was informed by participant observation and 49 interviews with professionals, patients, and families at three hospices in Denmark. The findings contribute to further understanding of the complexity of maintaining hospice philosophy in contemporary practice. Hospice practice works in an interpretive way with hospice philosophy to offer a “lived” philosophy and a means to an authentic death.

Keywords

hospice, hospice philosophy, hospice practice, good death, authenticity

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Introduction

The relatively young Danish hospices have developed a significant institutional framework for end-of-life care in Denmark and are known for good care based on strong values inspired by hospice philosophy (Dalgaard & Jacobsen, 2011; Timm, 2014; Timm & Hagedorn-Møller, 2013). The first Danish hospice opened in 1992, and today, there are 20 hospices, self-governing institutions, with an operational agreement with the Danish regions; these are political regions responsible for health care (Ministry of Health, 2017). Hospices are required by the National Health Service to deliver specialized palliative care, consultancy, teaching, research, and development (Danish Health Authorities, 2017).

Hospice philosophy developed from the principles Cicely Saunders formulated for St. Christopher's Hospice and formed the basis for providing good care for terminally ill and dying patients (Clark, 2018; Clark & Seymour, 1999; Woods, 2007; Graven, Thomsen, & Jacobsen, 2013). Saunders' (1996/2005) ambition for hospices was to create a homely and welcoming atmosphere in which the dying could find comfort and meaning at the end of life and die peacefully. To sustain a good death, hospice philosophy was underpinned by such values as openness, acceptance, and reconciliation (Clark, 1999a, 1999b). With a focus on care rather than cure, compassion, alongside a holistic and interdisciplinary approach to pain relief, became core ideals for hospice care (Clark, 1999b; Saunders, 1990; Saunders, 1965/2005). The physical environment of St Christopher's hospice catalyzed by hospice philosophy has recently been identified as a type of lifeworld organized to support and to engage patients in participation in the social sphere. This stands in contrast to hospitals' exclusion of patients from social life (West, Ontwuteaka-Philipsen, Philipsen, Higginson, & Pasman, 2019). Although hospice philosophy developed as a critical response to hospital care of the dying, Saunders (1978) nevertheless emphasized that medical science should provide a basis for palliative care and good symptom control.

Critics have noted the potential tension between the medical model and hospice philosophy values. Kearney (1992) and Bradshaw (1996) have argued that a reductive medical approach to symptom control runs the risk of reducing suffering at the end of life to "mere" symptoms and to lose focus on the values that hospice philosophy regard as central to a good death.

In contrast, other commentators have challenged hospice values as a normative social construction of a good death which in a palliative care context defines certain ways of dying as correct and others as bad (Hart, Sainsbury, & Short, 1998; Walter, 1994; Zimmerman, 2012). The impossibility of the ideal of *the* good death has been identified, and a "good enough death" has been suggested as a more realistic goal for individual ways of dying (McNamara, 2004).

Danish hospice literature is still sparse, but a literature review indicates that hospice philosophy does influence practice (Graven & Timm, 2017). Values such as open awareness of dying and a peaceful death are identified as core values (Dalgaard & Delmar, 2008; Graven, 2015; Steinfeldt, 2017). In addition, “time” and “space” feature as important elements for facilitating good care (Graven & Timm, 2017; Kjeldsen, 2017). This article examines how hospice philosophy is incorporated within contemporary Danish hospice practice to sustain a good death. By identifying the role of hospice philosophy in hospice practice, we can explore a contemporary interpretation of the ideal and discuss possible challenges for the ethos of hospice philosophy as guiding practice.

Theoretical Background

As a background for understanding how hospice philosophy is incorporated in practice, the study is theoretically informed by Berger and Luckmann’s (1966) sociology of knowledge. As pointed out by Berger and Luckmann, the reality of everyday life is constituted by a stock of knowledge that designates a framework for understanding reality. But the world of everyday life is not only taken for granted by its members. It is maintained as real through thoughts and actions of its members (Berger & Luckmann, 1966, p. 33). Drawing on this, perspective hospice philosophy shapes but is also shaped by everyday practice. Understanding how hospice philosophy as a stock of knowledge is incorporated into practice thus requires an insight into how it is maintained and provides meaning for everyday life at hospice.

Hospice philosophy is also shaped by contemporary culture on a macrolevel. To understand the role of hospice philosophy in contemporary hospice palliative care, the analysis is inspired by Taylor’s (1989, 1991) concept of authenticity. Taylor is critical of the interpretation of autonomy in what he describes as a culture characterized by a self-centered form of individualism. Autonomy, he argues, has become disconnected from our cultural sources. As he points out, our judgments are culturally situated within a horizon of significance. Self-interpretation is a dialogical process, and it is through an ongoing articulation of our moral vocabulary that we are enabled to make authentic judgements (Taylor, 1989). For example, our approach to death and dying is influenced by contemporary death ethos and hospice philosophy, and hospice philosophy can be understood as a professional, culturally situated, interpretation of the good death; but to provide meaning in a contemporary setting, it has to find its “right” interpretation through an ongoing dialogue. To explore the role of hospice philosophy in a secular and individualized context, the concept of authenticity is introduced as a framework for understanding hospice philosophy as an interpretive guide for an authentic death.

Methods

Design and Data

To explore how hospice philosophy is maintained and incorporated as an ideal for hospice practice, the study has focused on practitioners' hospice care plus patients' and loved ones' experiences with hospice. The research involved 7 weeks of participant observation including spontaneous and 49 semistructured interviews at three hospices in different regions of Denmark (May 2017–February 2018) (see Table 1). The fieldwork focused on how hospice philosophy was maintained and incorporated into hospice practice through social interaction and routines (Schutz & Luckmann, 1973). This involved a wide focus on everyday life activities of staff, patients, and relatives. The first author, V. G., adopted the role as observer and participant balanced between active participation in activities such as shared meals, church services, conversations with patients, relatives, staff, and volunteers and as observer in activities such as interdisciplinary conferences, conversations related to admission, medical examinations, and certification of death, nurses, and physiotherapists' working with patients (Kristiansen & Kroghstrup, 2016).

Spontaneous and planned semistructured interviews included staff, volunteers, patients, and relatives with the aim to capture a wide picture of good hospice practice was described (Kvale & Brinkmann, 2009). Data from spontaneous interviews were recorded in field notes. The semistructured interviews were recorded and transcribed. The study was approved by Research & Innovation Organization, University of Southern Denmark. All staff and family members were informed about the research and of the presence of V. G. at the hospices. Interviewees gave informed consent, and the data are anonymized.

Table 1. Overview of data.

Data/hospice	Hospice 1	Hospice 2	Hospice 3	In total
Hours of observation and estimated pages of field notes	104 hours 56 pages	82 hours 48 pages	88 hours 52 pages	274 hours 156 pages
Group interviews with nurses	2	2	2	6/25 persons
Individual interviews with staff	9	9	10	28
Individual interviews with volunteers	2	1	1	4
Individual interviews with patients	2	2	2	6
Individual interviews with relatives (r) or friends (f)	2	2	1	5
Interviews in total	17	16	16	49

Note. Adapted from Nielsen (2017).

Data Analysis

A phenomenological hermeneutic tool for analysis inspired by Kvale and Brinkmann (2009) was used. The first step of analysis was a phenomenological level. Commonsense knowledge as expressed by the “inhabitants” of hospice were here analyzed as source for insight into how hospice philosophy works in practice. Field notes and transcribed interviews were coded and followed by a thematic reading. Hereby core aspects of what, put together, appears as “hospice-inhabitants” commonsense interpretation of hospice practice was identified. On this level, data are presented in a form which is aiming to be close to everyday language and thus true to hospice philosophy as commonsense knowledge. The next hermeneutical step of analysis searched for an insight into underlying interpretations of hospice philosophy. This involved a theoretical reading inspired by Taylor’s concept of authenticity in order to gain an understanding of how conditions such as secularization and individualization affect maintenance work of hospice philosophy as a framework for the good death.

Analysis—Part I

The phenomenological analysis identified six themes as essential for hospice practice as described below.

Open Awareness of Dying

“Here, we don’t kick death out by the back door.” This statement was given by the hospice manager on the first day of V. G.’s fieldwork and referred to the ideal of an open awareness of dying which, as she pointed out, literally is demonstrated by a ceremonial tradition of following the casket and relatives out by the front door when a patient has died. At the three hospices, the concept of open awareness of dying worked as a guiding ideal which helped practitioners to adapt to the ways patients and relatives were coping with death and dying. For example, to make allowance for patients and relatives who found it overwhelming to see the coffin, they were informed before it was taken into public space. So though open awareness gave direction to hospice practice, it was not used rigidly to justify confronting patients and their family with the fact of death. As a medical doctor put it, “There is no recipe, it is not that they have to sit ‘upright’ in bed in a state of acceptance of a hospice-like picture of the good death.”

Openness was found to involve guiding the patient and loved ones through a process in ways that recognized that patients often fluctuated between a hope for cure or prolonging of life and acceptance of dying. The staff emphasized that the ideal of openness meant creating an opportunity for patients to express emotions such as grief, anxiety, and to share memories and thoughts about what is

important at the end of life. A nurse commented: “some patients and relatives hope so much for cure that they don’t live at all.”

The ideal of open awareness also worked as a professional response to patients’ uncertainty about the process of dying. As several nurses, priests, medical doctors, and music therapists commented, people are preoccupied with such uncertainties as “how do we say goodbye,” “how will the body react?,” “Will there be pain?,” and “What happens when the loved one is dead?” These questions were frequently addressed by staff and also through literature such as “Farewell at Hospice” produced by the hospices. Such documents provide written information about different ways of saying goodbye and suggest how rituals can be adapted to families’ wishes.

Thus, the ideal of open awareness was worked into hospice practices in varied and subtle ways, guiding patients toward acceptance of dying as an existential fact but also negotiated according to the patient’s own position.

Pain Relief and Peaceful Bodies

Hospice staff often mentioned “total pain” as a complex phenomenon related to the body in its individual context. “Palliative care is about optimum pain relief and what pain relief is for one patient might not be a relief for another” (medical doctor). An approach to pain expressed by several respondents saw the body as socially framed and that the body relieved of pain can become social again. As a physiotherapist stated, “Pain relief is about creating a framework which helps the patient to experience himself as something other than a body in agony which looks ugly and has changed so much because it is dying.”

There was wide agreement that the management of “total pain” required a holistic approach. This is consistent with Saunders’ approach to “total pain” (Clark, 1999b). Across the three hospices, it was observed how an interdisciplinary approach deployed a variety of “tools” including an advanced knowledge of pain relief and use of a range of interventions which complemented each other. This strategy enabled both medical means of pain relief, getting the medicine which worked, but also, for example, finding the right kind of food at the right time. Pain relief might equally involve a massage or music therapy, a conversation, or some other intervention to enable the patient to become a social body again. As one relative captured this holistic approach, “It is everything which makes it work.” Staff often expressed the nature of pain relief as enabling the patient “to find peace.” The fieldwork revealed that staff often discussed and were preoccupied with the idea that to bring such peace to the patient required an acute awareness of the lived experiences of the dying body. Knowledge of the individual nature of a particular patient’s distress would enable a tailored holistic approach. Thus, holistic pain relief emphasized the authenticity of each patient’s experiences. This interpretation of holism was incorporated in practice as an awareness of the whole body’s suffering including

not only targeting specific symptoms but also helping the dying person to be reestablished as a social being.

Hospice-Time

Danish hospice practice had an important temporal dimension. Often staff used the phrase “hospice-time” as referring to a pace which symbolized that “we are not busy” and that “we have time for you.” Patients, relatives, and staff often emphasized the fact that there was time for the patients. “Even if they might be busy it is still peaceful and exudes time for the patients” (handyman). Aiming at making space for significant moments “hospice-time” also involved “timing” understood as when to prioritize “professional” tasks with the patients, for example, to delay cleaning a wound until after the visit of a loved one or to adjust medicine to a patient’s wish to be awake rather than being “pain free.” The findings reveal that this focus on time understood as a subjective time related to meaning was reflected in an awareness of and space for “great moments” or “moments of meaning” such as a wedding or a baptism at the hospice, family members being brought together, to say good bye or simply to a moment of peace.

“Hospice-time” and presence appeared as closely related. In group conversations with nurses but also among other staff groups, the importance of being present in the moment was underlined. “We listen with our heart and our judgment of what is important instead of acting blindly directed by 10 bells ringing” (nurse).

In practice, “clock-time” was to some extent directing daily routines, the nurses’ bells did ring, and different groups of staff could only see so many patients. However, the general picture which was drawn by patients, relatives, and staff was that time, being present and attentive was considered a core focus of care. This echoes the often quoted reference used by Saunders (1965/2005): “watch with me,” a reminder of being attentive to the patient (p. 2). In the Danish context, this ideal was clearly guiding the interpretation of time toward a focus on meaningful time which would help the dying person to find peace.

Feeling Safe

Patients and relatives often reported that hospice made them feel safe. Being safe related to being “looked after” or to someone “taking over” often after a stressful time at home where everyday life was difficult to handle because of pain and lack of ability for self-care. As one among several patients expressed the change from being at home to staying at hospice, “my life was a vicious spiral and then I came here, and I enjoy it and my family can visit without thinking that I cannot manage it.” For patients who lived on their own being in a hospice relieved their

anxiety about dying alone. “I know that I’ll not be found after lying there dead 2 or 3 days” (patient).

The experience of loss of ability for self-care was painful not only for the patients but also for relatives. This loss was often negotiated in the triad of staff, patients, and relatives because it could be difficult to receive help whether it was patients who needed help to get dressed, to move, to eat, and so on, or relatives who needed somebody to take over from the role as main carer: “I often see that people who come here from home and have been used to looking after themselves find it hard to take that we want to help. Some of them say that they don’t want to cause trouble” (hospice manager).

The findings reflect Saunders’ (1965/2005) idea of hospice as a community which by analogy with family is characterized by the hospitality of a good home in which the patient and family can “relax in security” (p. 5). In this study, the hospices can be seen as caring communities in which powerlessness and dependency are permissible thus freeing the patients to spend their strength on what really matter to them. A relational approach to dying understood as a shared responsibility for the dying and family permeated the atmosphere at the hospices but as illustrated below an analogy of hospice as home was complex.

Homeliness

At one of the hospices, V. G. was welcomed by the sound of people singing and recognized the smell of home baked bread. At this hospice, the morning coffee (like the other meals) was a daily social event for patients, relatives, volunteers, and staff with the aim to “invite” everyday life into hospice. “We often meet; especially relatives but also patients who have great moments and forget that they are ill because they sit here and talk like everybody else” (hospice manager). Homeliness was here expressed as a guiding value with an explicit reference to Saunders ideal of “living until you die” (Saunders in Clark, 1999a). At all the hospices, the volunteers sustained this idea of bringing everyday life into hospice by being hosts at meals, taking patients out for a walk, or organizing music events, bar evenings, and so on. The daily routines were different at the three hospices and the balance between creating a homely atmosphere and being an institution delivering professional palliative care was prioritized differently. At one hospice, it was emphasized by a manager that they wanted to send the signal of being an institution which delivers professional palliative care and to dismiss prejudices about good palliative care being simply “home baked bread and a cat at the foot of the bed.” However, at all the hospices, the atmosphere was described by patients, relatives, and volunteers with words such as “homely,” “warm,” “peaceful,” and “welcoming” with the architecture itself showing that “somebody has made an effort” all of which was experienced as symbols of being valued. The spatial aspect of hospice involved an existential dimension

evident in such things as a sense garden, green house, or through religious services and music events. Such spaces could invite a “spiritual” moment for patients, creating spaces for thoughts and emotions about death and dying as one patient said: “I often sit here (conservatory) and think big thoughts or perhaps only small ones which is good enough—the peace and balance it gives your soul means a lot.”

It was obvious that Saunders’ ideal of hospice as “somewhere between a hospital and a home” (Saunders in Amin, 2015, p. 1) inspired hospice practice, but it varied how the ideal literally referred to creating a space which encouraged a sense of community. A shared approach was directed toward creating an atmosphere of existential belonging in which the dying could feel “home” as social beings despite the unknown state of dying.

Contrasting Ideals for Hospice Practice

Hospice practice has to cooperate/compete with other ideals for practice such as evidence-based practice (EBP) and managerial strategies. EBP in the form of quantitative assessment tools does not always sit easily with the more narrative and holistic hospice philosophy. For example, all the hospices use the questionnaire EORTC-QLQ-C15-PAL as a tool for assessing quality of life (Danish Multidisciplinary Cancer Group for Palliative Care, 2017). However, some nurses, criticized the tool for being reductionist; too focused on specific symptoms instead of paying attention to the problems, the patients were most occupied with. Thus, it was sometimes questioned whether the measured “qualities” reflect what is really important for the patient’s quality of life. The EORTC was supposed to be completed prior to the initial clinical assessment. Some nurses saw this as creating an obstacle to the development of relationships which sustained holistic care. One nurse said

The patients who come here are really really ill, and often they are scared of coming here. So I think that I am inhibited in creating a relationship. A lot of them experience it as a kind of exam having to respond to, on a scale from 1 to 4, am I short of breath. (. . .) when I meet a patient it is about making him feel that here we take care of you.

Managerial strategies for patient flow including criteria for admission and discharge were also a cause of tension. Being discharged from hospice if identified needs for specialized palliative care have been taken care of is part of the reality at hospice. And several patients are discharged for a period of time and then return to hospice if needed. Sometimes, this possibility supported patients’ in navigating between an awareness of dying and a hope for prolonging life: “I somehow look forward to go home and do some more training but I am going back here to die. I am happy that I know what it (hospice) is and that we

have a plan” (patient). For other families, it was considered a risk to be discharged and caused worries and frustrations for both families and staff. A worry was that the patient might be discharged to a lower standard of care than hospices provide. “When we discharge patients I often think that we cause suffering” (nurse). The issue of having to cut off patients’ time at hospice against their wishes seemed to replace safety and belonging with uncertainty.

Analysis—Part 2

Hospice Philosophy as “a Stock of Knowledge”

Hospice practice appeared in this study as ongoing maintenance of hospice philosophy. As a “stock of knowledge” (Berger & Luckmann, 1966), hospice philosophy is incorporated into the way hospice practice is organized, articulated, and lived in everyday practice. Maintenance work involved adapting hospice philosophical ideals of a good death such as open awareness and acceptance of dying to the patients’ own position. Also a holistic approach to pain relief was adapted to patients “lived lives”. For example, some patients preferred being alert rather than being sedated. Hospice practice aimed at creating hospice as a safe and homely space for the dying and families. The themes identified in the study are examples of how hospice philosophy works as an institutionalized normative framework for hospice practice in a way which finds substantial form through an ongoing process of interpretation in the social interaction between staff, patients, and families.

To get a further understanding of hospice philosophy’s role in contemporary hospice practice, we will explore it as an interpretative framework for the good death related to the concept of authenticity.

From Good to Authentic Death

Hospice philosophy has been criticized for being overly normative defining the “right way” of dying (Hart et al., 1998; Zimmerman, 2012). This study confirms that in practice the ideal of acceptance of dying as component of the good death plays an important role within the normative framework for practice. However, this study reveals that at the microlevel the ideal of the good death works contingently and is pragmatically interpreted to the context of the individual patient and their family. The ideals of hospice philosophy are guiding but not stipulative for hospice practice. Practices informed by these ideals are shaped by social and cultural elements as well as individual patient’s needs, beliefs, family background, and different ideas about dying. For example, “acceptance of dying” does not in practice dictate that a patient be confronted

with their imminent death they are not ready for it. This pragmatic turn in Danish hospice practice could be seen as a response to what through decades has been described as a secular and individualized culture (e.g., Giddens, 1990; Taylor, 1989; Weber, 1920/2011). This tendency is also described in the context of death and dying as a demand for more choice and individuality in death and mourning rituals with the consequence that questions related to death and dying requires an ongoing dialogue of what good dying and death means (Jacobsen, 2014, 2016; Walter, 1994). As also emphasized by Broom and Kirby (2013), a challenge for hospice practice is that due to secularization and individualization, standardized solutions are increasingly problematic for managing end of life. A secular and individualized culture points to the importance of a reflexive approach to hospice practice and one could even question if hospice philosophy is still necessary as a framework for sustaining a good death. However, the findings in this study show that people are preoccupied with such uncertainties about death and dying and actively seek professional guidance. As Bauman (1992) argues, a consequence of secularization is the absence of a shared language by which to articulate death. Hospice philosophy can be said to meet this challenge because it provides a language within which to articulate “end of life issues.”

In addition to providing a language with which to articulate death and dying, hospice philosophy can also provide a guiding framework as also Graven (2015) observed in a study of hospices nurses’ approach to spiritual care. Hospice philosophy seems to provide a normative framework, understood as Taylor (1989) puts it, a “moral vocabulary” associated with the concept of authenticity. For Taylor, human beings are interpretive and culturally situated creatures. This means that self-interpretation, for example, defining an authentic idea of the good death, is a process that takes place within a cultural moral vocabulary. This vocabulary of the good death provides a normative horizon for self-interpretation. Thus, the concept of authenticity is individual but also socially situated (Taylor, 1989). Drawing on this definition of authenticity, authentic dying is not only an individual matter but also socially informed and hospice philosophy can be understood as a culturally situated vocabulary within which the good death can be articulated. From this perspective, hospice practice works toward delivering a “good death” by means of ongoing interpretation work directed toward authentic dying. As such, hospice philosophy does not define the good death but delivers an institutionalized vocabulary related to death and dying that is adapted to individual needs and wishes.

Below the findings are discussed; first, an interpretive approach to hospice philosophy is briefly discussed related to the concept of individualization, and secondly, the identified tensions are discussed as examples of possible clashes with hospice philosophy as guiding hospice practice.

Discussion

In an era of individualization, the interpretation of hospice has to navigate in a complex of demands. West et al. (2019) describe the “growing move toward providing single rooms (...) as a fundamental departure from the way that St Christopher’s was designed to deal with the dying patient” and understand it as a “nod to a consumer-led, customizable culture of current society” (p. 400). They see it as a possible move away from hospice as a shared “lifeworld” adapted to the needs of dying people. Our study finds that also in contemporary settings (all of which have single rooms) hospices have these lifeworld qualities and help to reestablish dying persons as social bodies, but the interpretation of “home” as a spatial concept varied at the three hospices. A shared interpretation of the concept of homeliness was better captured with the concept of existential belonging. The variety in interpretation of the ideal of homeliness identified in our study can be understood as examples of different ways of interpreting hospice environment adapted to an individualized culture but also to a reality in which hospice for several patients is a temporary place as being discharged from hospice has become “normal.” As a hospice manager said, “hospices today are not necessarily a place to die but a place for learning how to die.”

Another example of how hospice practice has to find its self-interpretation within contemporary interpretation of autonomy is illustrated by the approach to care. Our findings characterize hospices as a contrast to what Taylor (1991) describes as a self-centered interpretation of the concept of autonomy with a focus on the isolated self. We find that hospices work as caring communities in which powerlessness and dependency are considered as a part of human condition and thus appear as a critical contrast to contemporary ideals of patient autonomy focusing on self-care and independence.

Taylor (1989) emphasizes that it is through dialogue we become more articulate within our moral horizon. Finding “the right” interpretation of hospice philosophy requires that the nature of hospice philosophy as guide for an authentic death is articulated not only in the face-to-face meeting with patients and families but also at institutional level in each contextual practice. This includes an ongoing dialogue about the meaning of substantive ideals such as open awareness, acceptance, homeliness, safeness, and so on.

Maintaining the Ethos of Hospice Philosophy Among Competing Ideals

Perhaps the biggest challenge for hospice practice arises from the identified tensions with competing ideals implicit within EBP and managerial strategies that are increasingly part of palliative care services. Such conflicts illustrate that maintaining and incorporating hospice philosophy into practice not only

involves adapting the ideal to culturally situated interpretations of the good death as discussed earlier. It also involves navigating through what has been discussed as an increasingly medicalized, routinized, and bureaucratized landscape of palliative care, all of which challenge hospice philosophy's ethos of care (Bradshaw, 1996; Clark & Seymour, 1999; Graven, Woods, & Jacobsen, 2016; James & Field, 1992; Kearney, 1992; McNamara, 2004). Traditionally, the ethos of hospice philosophy was based on the idea that dying is a burden to carry rather than a problem to be solved. In one of her later writings, Saunders (1996/2005) acknowledged the difficult balance between a holistic and a symptom-oriented approach and wrote, with a reference to the hospice physician Michael Kearney who emphasized a holistic approach: "Palliative care physicians are not to be merely 'symptomologists.'" And she emphasized "that a person is an indivisible entity, a physical and a spiritual being" (p. 35).

In an Australian study of whether the "good death ideal," as central to the hospice philosophy is compatible with the institutionalization of hospice care McNamara et al. find that nurses "hold firm in the belief that death is made 'good' by peaceful acceptance on the part of the patient." However, the authors also emphasizes the impossibility of this ideal. In her later article, McNamara (2004) suggests the concept of "the good enough death" as an ideal for hospice practice because a "return to routine medical practices and a hierarchy of care (...) prioritizes the physical management of symptoms" (p. 929). She finds that medicalization of palliative care has changed the language and suggests the claim that in a culture without a certain existential language of dying a more certain medical language of pain is prioritized.

The younger Danish hospice context works within a medical system in which palliative care is not a medical specialty and the hospice managers at most hospices are nurses. As discussed earlier, hospice philosophy as a normative framework for dying is no doubt incorporated as a core source for meaning in the Danish context for our study. However, the tensions identified in our study also point to concerns that echo the critical warnings about losing focus on the ethos of hospice philosophy. The EORTC survey is one among other examples of tools discussed as problematic in hospice practice. A core issue here is the critique questioning the possibilities for reaching a mutual understanding with the patients given the circumstances for using this tool. A point also made in a Danish study on the use of EORTC in cancer rehabilitation (Hansen & Tjoernhoej-Hansen, 2013). As they emphasize, the EORTC questionnaire neither recognizes a narrative approach nor takes the context of using the measure into account. Tensions related to criteria for admission and discharge concern the managerial demands focused on efficiency and goal rationality that conflict with the ideals of hospice as a place of safety and existential belonging. The nature of these tensions is too complex for a proper discussion here, but they indicate that hospice practice as informed by hospice philosophy clashes when

instrumental and strategic goals for care replace the relational ethos of hospice philosophy.

Hospice philosophy aims to help people toward what is here suggested to be conceptualized as an “authentic death,” and as this study acknowledges this is not done through standard solutions but requires environments in which the good death is interpreted holistically as a physical, psychological, social, and spiritual event. To create such environments requires skills and resources to gain a shared understanding of the needs of dying people. Among these resources are time and the spatial aspects of hospice directed toward giving patients individual attention and enabling them to feel “home” despite the unknown situation of dying. Such less measurable qualities appear as crucial for the nature of hospice practice as informed by hospice philosophy.

Strengths and Limitations of the Study

This study is the first Danish exploration of the relationship between hospice philosophy and hospice practice. Drawing on a substantial empirical study, the findings contribute to further understanding of the complexity of maintaining hospice philosophy in contemporary hospice palliative care. However, it has to be considered that the fieldwork took place on 3 of the 20 hospices in the Denmark, and the external validity is thus limited by possible cultural differences from other hospices.

Conclusion

The results of the study reinforce the relevance of hospice philosophy in Danish hospice practice as a “lived” philosophy which works as an interpretive practice to sustain an authentic death rather than being a set of fixed institutionalized values. An “authentic death” as a possible ideal for hospice philosophy is our, albeit tentative, suggestion of an interpretive approach to the question of the good death. Within a health-care system with an increased focus on measurable evidence for practice and demands for efficiency, maintaining hospice philosophy as a fundamental guide for practice is challenging. To maintain its place, it is necessary to both articulate and also to prioritize the ethos of hospice philosophy. The identified challenges to hospice practice are the tensions related to EBP and managerial strategies and point to the need for further research to explore how such tensions might be reconciled within the reflexive framework of hospice practice.

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Ethical Approval

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