



AALBORG UNIVERSITY
DENMARK

Aalborg Universitet

Hospice Care

Between Existential and Medical Hope

Graven, Vibeke; Petersen, Anders; Timm, Helle Ussing

Published in:
Mortality

DOI (link to publication from Publisher):
[10.1080/13576275.2020.1803249](https://doi.org/10.1080/13576275.2020.1803249)

Creative Commons License
CC BY-NC 4.0

Publication date:
2021

Document Version
Accepted author manuscript, peer reviewed version

[Link to publication from Aalborg University](#)

Citation for published version (APA):
Graven, V., Petersen, A., & Timm, H. U. (2021). Hospice Care: Between Existential and Medical Hope. *Mortality*, 26(3), 326-342. Advance online publication. <https://doi.org/10.1080/13576275.2020.1803249>

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal -

Take down policy

If you believe that this document breaches copyright please contact us at vbn@aub.aau.dk providing details, and we will remove access to the work immediately and investigate your claim.

Danish Hospice Care: Between Existential and Medical Hope

Medicalisation of hospice care has been discussed simultaneously with the development of palliative care into a medical specialty. However empirical knowledge of the role of medicalisation in hospice practice is underexplored. This paper considers hospice managers' perspectives on hospice care in the complex between values related to hospice philosophy and a specialised medical approach to hospice care. Focus groups and small group interviews were conducted with hospice managers from 16 out of the 19 Danish hospices. Drawing on hope as a theoretical framework, the study contributes to further understanding of the complexity of navigating hospice care in the impasse between an existential hope focused on meaning at the end of life and a medical hope for control of the dying body. Hospice care appeared as pulled between these dimensions of hope. The hospice managers took a pragmatic approach to medicalisation but their emphasis on dying as an existential event also points to a role for hospices as a critical voice against over-medicalisation of dying.

Keywords: hospice, hope, medicalisation, hospice philosophy, hospice care, existential

Introduction

The modern hospice movement and its philosophy of care developed as part of a wider critique of the hospitalisation of dying in Western societies raised by the death awareness movement (see for example Ariès, 1981; Feifel 1959; Glaser & Strauss 1965; Kübler-Ross 1969). Cicely Saunders, a leading figure of the modern hospice movement argued that the way a society treats the dying reflects its fundamental values: 'A society which shuns the dying must have an incomplete philosophy' (Saunders, 1961, p.50). She found it necessary to create a 'special place or community for the

dying, what she called “a stopping place for pilgrims” (Saunders in Woods, 2007, p., 54). The idea was to create an institution for dying people in which death was considered a natural part of life. The foundational idea of hospices, later phrased as ‘hospice philosophy’, was to help dying people to a good and peaceful death characterized by values such as open awareness, acceptance and reconciliation with dying. These values were related to an ideal of helping people to live a meaningful life until they die (Saunders, 2005; Clark, 2018).

Even though hospice developed as a critical response to medicine, medicine has continued to be central to hospice care. The discussion of medicine’s role and the medicalisation of dying have continued to be the subject of debate with regard to the development of hospice care into palliative care (Kearney, 1992; Clark & Seymour, 1999; Clark, 2002; McNamara, 2004; Floriani & Rolland, 2012; Robinson, Gott, Gardiner, Ingleton, 2017). The development of palliative care as a medical specialty has gradually changed the register from religiously grounded values to a more secular humanistic ones, ‘a universal register acknowledging “human dignity” and “quality of life”’ (ten Have & Clark, 2002, p. 6). David Clark (2016) describes how palliative medicine in the mid-twentieth century developed with a focus on cancer pain and pain management research aiming for recognition ‘within the medical establishment as a legitimate field of medical specialisation’ (Clark 2016:150). In an earlier paper Clark describes how the medicalisation of palliative care developed a scientific and secular approach to dying characteristic of late modernity:

...a specialty that opens up a space somewhere between the hope of cure and the acceptance of death. In doing so, it makes a classic appeal to the desires of “patients” in a modern culture, where we dread not so much the state of death as

the process of dying. In this sense it is more appropriate to view medicalisation as the expected rather than unintended outcome of the growth of palliative care (Clark, 2002, p., 907).

Critical voices from within the field of hospice care have described what they see as the consequence of professionalisation and bureaucratisation amounting to a challenge for the hospice movement's ideals (Seale 1989, James & Field 1992). Bradshaw (1996, p., 411) tellingly refers to Christian virtues like 'compassion' and 'vocation' as central to the ethos of hospice philosophy and she warns that 'care applied according to a formula would become mere technique devoid of compassion.'

Concerns about the consequences of medicalisation have been less explicit in the Danish context. Danish hospices have a relatively short history, the first hospice opened in 1992 and today there are 19 in-patient hospices (for adults) with 256 beds. 92,5 % of hospice patients in Denmark have cancer (Hansen, Andersen & Groenvold, 2019). National criteria for admission to hospice requires that the patient has ceased curative treatment and has a short life expectancy (DMCG-pal, 2017). In Denmark palliative care is not a medical specialty as in some other countries such as the UK. It is considered a medical sub-specialty involving medical specialists in areas relevant for palliative care, who have received additional training and work full time with specialised palliative care (Danish Healthcare Authorities, 2017). The Danish hospices, like many other modern hospices, have a Christian heritage and are acknowledged as providing a high standard of palliative care based on the values of hospice philosophy. They have an influential voice in the development of palliative care (Timm, 2014; Graven & Timm, 2019). Though Danish hospices developed from private initiatives they are today included in the tax-based healthcare system as self-governing

institutions, with an operational agreement with individual local authorities, that in turn are responsible for healthcare provision (Ministry of Health, 2017). Hospices fall under the jurisdiction of the hospital law and are required by the National Health Service to deliver specialized palliative care, consultancy, teaching, research and development (Danish Healthcare Authorities, 2017). With the exception of one, all hospice managers are nurses. These particular features of Danish hospices are of interest because they can be seen as contributing to the creation of an ambiguity as to the place, role and function of the hospice institution. How Danish hospices navigate within the complex balance between medical specialisation and a wider care approach founded on the values drawn from hospice philosophy has so far only been sparsely explored (Graven & Timm, 2017). As widely recognised in palliative care literature, hope is a core - but also complex - phenomenon at the end of life. Drawing on existential philosophy several studies describe the importance of sustaining hope, understood as a dimension of being, at the end of life. Studies referring to this existential dimension of hope point to aspects such as loving relationships, memories and reconciliation with death as hope sustaining (see for example Gerrard & Wrigley, 2009; Benzein, Norberg & Saveman, 2001). With its focus on being at the end of life, hospices as institutions obviously represent a contrast to a medical hope for survival or prolonging of life. Drawing on the concept of 'hope' as a conceptual framework the aim of this study was to explore Danish hospice managers' (HM) perspectives on hospice care and the complexity of maintaining hospice values in an increasingly medicalised service.

Methods and analytical framework

Research methods

The study had an explorative design. Data were collected by means of two

focus group interviews with thirteen HM from different hospices in Denmark, and three small group interviews with respectively two and three HM. Four of the nineteen Danish hospices for adults have an out-reach, sometimes home-based, specialized palliative care service. The main part of the home-based specialized palliative care is delivered by specialized palliative care teams based in hospitals and thus not included in this study. Danish HM are organised in the Organisation of Hospice Managers in Denmark, a management forum with the aim to develop visions and strategies for Danish palliative care (Hospicemanagers.dk). By interviewing HM we gained knowledge about their views and reflections on core values and conditions driving contemporary hospice care. Altogether 16 of the 19 Danish hospices are represented in the interviews conducted. HM from three hospices gave their apologies for practical reasons.

The two, two-hour, focus group interviews were conducted by authors known by the HM as palliative care researcher/head of research in the field. An insight into the field, without being directly involved in practice, seemed to encourage an open dialogue and reflection. The HM were asked four main questions: What is hospice philosophy today? How has the task for hospices changed over time? Which extrinsic factors are directing/influencing your everyday practice? And what are the future perspectives for hospices?

The small one-hour group interviews with HM from three hospices were conducted by VG in relation to an ethnographic study focused on how hospice philosophy is maintained in hospice practice (Graven & Timm 2019). These interviews focused on similar questions as the focus group interviews but allowed more detailed descriptions to be provided based on the interviewers' observations as starting point for

reflection of specific cases.

All of the interviews were recorded and transcribed. The HM were informed about the purpose of the interviews by email. Further, before the interview they were informed that the data they provided would only be used for research purposes and would be anonymized by changing names and avoiding mentioning names of hospices. The hospice field in DK is small and a complete anonymization is difficult as some HM's position might be recognized within the field. This issue was addressed and the HM were informed that they would be able to withdraw from the study within a month after the interviews. All HM gave their written informed consent. In general, the interviews were characterised by an open conversation. However, examples of attempts to avoid disagreement were observed and this could be due to a perceived risk of being quoted but probably also reflected an attempt to "speaking with one voice" as members of the Organisation of Danish Hospice Managers. The study was approved by Research & Innovation Organization, University of Southern Denmark.

Analytical framework

As a framework for analysis we were inspired by two theoretical constructs: an existential phenomenological perspective on hope and the sociological concept of medicalisation.

French philosopher Gabriel Marcel's theory of hope distinguishes two kinds of hope: 'to hope that' and 'to hope' (Marcel, 1951). 'To hope that' refers to a concrete future directed hope which might be seen as aligning with a clinical goal such as the hope of a cure. In this analysis 'hope that' is associated with what we shall refer to as medical palliative care. In contrast 'to hope' is to adopt an ontological stance that

captures a mode of being in the world. Marcel points out that ‘to hope’ is something transcendent, not to be found in specific wishes or concrete goals but is reflected in the person’s relationship to the world and others, because the trust and security people find in being related to others is infused with hope. Thus ‘to hope’, according to Marcel embraces the entire human existence and is here referred to as existential hope. This dimension of hope cannot be reduced to a psychological capacity within an individual but is received from being in the world. As Marcel puts it – hope is a mystery to be ‘explored’ rather than ‘dealt with’ (Marcel 1951p.35). This existential hope is a ‘patient hope’ because it is ‘a “positive non-acceptance” of life’s trials and tragedies’ (Webb 2007, p.69).

Hospice is not only a philosophy of care but also an institution embedded within the contemporary Danish healthcare system. We use the concept of medicalisation as developed by Conrad (1992) as an orienting concept for exploring the implications of hospices as incorporated within the established healthcare system and the development of palliative care as a medical specialty or (as in Denmark), sub-specialty. Conrad describes medicalisation as the process of defining an increasing number of life’s problems as medical problems. Medicalisation at the conceptual level is reflected in the use of a medical vocabulary (or model) to order or define the problem at hand. Medicalisation at the institutional level points to organisations’ adoption of a medical approach to treating a particular problem in which the organisation specialises (Conrad, 1992, p. 211).

Data-analysis

A phenomenological hermeneutic tool for analysis inspired by Kvale and Brinkmann (2009) was used. The transcribed interviews were coded followed by a

thematic reading. The first step of analysis was a phenomenological one, used to explore existential aspects of hospice care. On this level data are presented as reflective phenomenological writing (van Manen, 1990) which involves utilizing Marcel's existential 'to hope' as analytical inspiration for describing essential meaning structures of HM perspectives on hospice care. The next hermeneutical step of analysis searched for an insight into hospices as socially embedded within the established healthcare system and palliative care. This involved utilising medicalisation as a conceptual framework for interpretation of the status and revisionary pressures influencing hospices as healthcare institutions.

Analysis part 1 – Existential hope

Hospice philosophy

When being asked the question: 'What is hospice philosophy today?' the HM echoed traditional hospice philosophy as illustrated by the following comments: 'We have a strong view on human nature inspired by hospice philosophy' (Alice) and 'We agree that hospice philosophy is a fabulous point of departure and we have got it from the "hospice-mother"' [Cicely Saunders] (Dorthe).

Holistic care and an interdisciplinary approach were reported as 'something we should never sell out' (Ida) in order to maintain hospice's institutional focus on the individual patient. A family approach to care was also emphasised as crucial; a hospice as an institution reaches 'further than the individual persons' life (...) we embrace the family so that the stay at hospice reaches into the future life of the loved ones' (Pia). To illustrate the family approach alongside the importance of seeing the individual as individual, a hospice manager gave an example from her hospice which was clearly

recognised by the other participants:

Ulla: We had this relative, when she and her husband arrived, the nurse said hello to him and was present and attentive as they are at all hospices and she welcomed him by his name. And then she welcomed the wife by her name. The wife now broke down in tears and said: “this is the first time ever in my husbands’ care I have felt that I was seen – nobody has ever before called me by name”. Suddenly she could feel her name, one might say, in this entire professional world and see herself as a person and not just the one who is with her husband.

The HM approach to hospice philosophy as care directed to the dying person and their family, reflects what Saunders described as the role of hospice carers in recognising and accompanying the patient in their journey towards the end of life. In what follows we explore the nature of hospice philosophy further by means of the concept of hope.

Being at the end of life – a ‘patient’ hope

The HM were unanimous in regarding hospice care as providing a way of helping the dying person to move away from a medical language of ‘cure’ and ‘life prolonging treatment’ towards a more existential language of meaning in which it might be possible to talk with open awareness of dying. Here the Marcelian language of hope is pertinent to understanding hospice care as helping to transcend the concrete hope for cure or prolonging of life, to a language related to being, ‘to hope’. What this ‘being’ at the end of life actually means was illustrated by the HM’s’ reflections on helping patients to be reconciled with their dying.

Lise: When they come to us they suddenly get a different approach to what is

valuable to them. And I think this is because we have time and courage to talk with the patients and the loved ones about what we see. Asking them about their thoughts is crucial instead of just offering this and this treatment: “would you like it or not?” (...) We are not afraid of talking about dying and having to let go of everything and we can help the patients to say: “Now I want this because it is meaningful right now in my last time of life.”

Lene: They slowly find out that it is not worth spending time on treatment (when there is no cure) but on what is important now.

Noticeable in these and similar responses is an attempt to utilise an existential language of ‘being’ and to open up for the dimension of hope as described by Marcel. The existential hope refers to what can be phrased as ‘hope against hope’ (Garrard & Wrigley, 2009) as for most hospice patients’ survival is unlikely but yet there is still hope to be found. The HM saw hospice care as assisting the patient in this journey, moving away from hoping that a treatment or cure will materialise, towards the disposition to hope. The HM regarded a fixation on concrete hopes for treatment or cure as potential barriers to living the life that is left. Marcel describes this characteristic of the existential hope as an ‘absolute hope’, unconditioned by the circumstances, hope that transcends disappointments and despair (Marcel, 1951, p.46). To sustain this transcendence the HM emphasised awareness on existential aspects of pain:

Jane: How we talk with people about what hurts and is difficult and what is meaningful and gives hope or is meaningless. Because we are educated in a healthcare system focused on being clinically skilled and we have to be damn good clinically but also always think in a way that when the patient says “I am in pain”, then it does not necessarily mean that you immediately grab the

paracetamol or morphine but also attend to the existential aspects.

Marcel's characterisation of hope as a 'patient hope' clearly reflects this approach to dying. This existential hope is not directed towards changing the conditions but towards finding hope despite the reality of living with a terminal illness.

Virtue based care

The HM used words such as 'love', 'authenticity', 'compassion', 'altruism', 'spirit of openness among staff', 'presence' to describe their ideals of hospice care. Using such words gave emphasis to the virtues HM regarded both as foundational within the hospice philosophy of care and, as mentioned in all the interviews, required for being a good hospice 'worker'. Some HM even argued that hospice staff should regard their work as the vocation to be highly attentive to their patients and close ones. Compassionate care and the associated virtues were seen as a necessary part of hospice identity. The explicit talk of 'love' as part of this identity was discussed by the HM:

Britta: I think there is a lot of love, not the love you have for your loved ones at home, but compassion (...) and love sends warm-heartedness to the individual patient, the family and to whatever you are doing (...). I experience love and compassion as showing the way, also for the staff; and I think there is limited space for love in many other systems but I think there is space for it here.

Rikke: I have never been at a work place with so highly specialised staff (...) I have always said that we have to be professional, but also, that you cannot work at a hospice if you don't get "disturbed" and now and then get a little scar, otherwise we would be just wage earners, and we cannot have that at a hospice.

Jane: I am sure that the presence and authenticity in the relationships is what we

are recognized for as hospices, because you are met and seen. And it is not when you are met by a professional shell but by a real human being that the hospice is at its best.

These virtues reflect the vocational attitude of traditional hospice philosophy, yet in a more secular vocabulary in that Christianity was not explicitly mentioned. As one hospice manager observed later in the dialogue:

Alice: I wonder how Cicely Saunders' strong faith reflected in hospice philosophy leaves its marks on us today. Because you say "love" and you say "compassion" and "altruism". Saunders formulated hospice philosophy within a Christian framework and we do not necessarily do that today, but I should like to know if it is the same values of compassion that carries it through.

The HM's emphasis on virtue based care helps to articulate further a relational dimension of hope incorporated in the HM's views on hospice philosophy.

Care as hope sustaining

By emphasising the importance of being with the patient and family at the end of life, the HM's illustrated their commonly held belief that dying is a relational matter, the shared responsibility of patient, family and professionals. The family and patients' existential journey at the end of life was described as a process sustained by the staff in order to explore hope and meaning for the individual patient:

Gitte: I see the skills for unconditional acceptance as a kind of altruism incorporated in this profession to think about a higher level for the person...

Signe: Yes, they (the staff) embrace them (the different types of families) so that

they find dignity and hope in the last part of their lives. And I think this is something unique for an institution within our healthcare system.

HM also described a ‘wondering’ or explorative approach as being required by the hospice staff as they accompany the dying on the journey at the end of life. As a hospice manager expressed it: ‘This [hospice philosophy] is also about being able to be in the open and not to think there is an answer for everything (...) but to accompany the patient and figure out where your hope or your words can take us’ (Ida). This explorative approach to hope and meaning reflects Marcel’s idea of the existential status of hope: ‘hope is a mystery and not a problem’ (Marcel 1951:35). The HM’s emphasis on love and compassion as foundational for care clarifies existential hope as a dimension of hospice care. Marcel points out: ‘hope is only possible on the level of the us, or we might say of the agape¹, and it does not exist on the level of the solitary ego, self-hypnotised and concentrating exclusively on individual aims’ (Marcel, 1951, p.10). The introductory quote in this section illustrates this idea. The woman was called by her name and thus re-established as a human being through the carers’ attentiveness. The essence of hope as it also emerges from the interviews is that it refers to a disposition. With reference to Marcel the situation can be described ‘as before but better than before’ (Marcel 1951, p.67) – the woman’s situation is still hopeless in so far as her husband is dying but the example illustrates that being recognized as a person sustains her. The point here is to understand hope as received through our connectedness to the world. According to Marcel love is the incarnation of hope by virtue of the specific but also transcendent character of love (Marcel 1951, p.67). Specific actions of love are incarnated or we could say embodied as lived experiences of actually being connected

¹ Agape refers to love as a sacrificial love and not as romantic or sexual love.

to the world: an ‘absolute Thou in whom I must hope’ (Marcel 1951, p. 61). In other words experiences of love (for example the experience of being recognised as a human being by an attentive nurse) have the potential to evoke hope. The virtue based care emphasised by the HM as foundational thus appear as hope sustaining because love, understood as, being attentive, compassionate, authentic etc. potentially evoke a hopeful perspective.

To sum up, the HM’s reflections on hospice philosophy can be seen in terms of Marcel’s existential dimensions of hope. The existential dimension of hope is a ‘patient’ hope directed towards living a meaningful life as a dying person. The situation of the dying person and their family was considered by the HM as the starting point and required a wondering approach to care directed towards exploring meaning and hope at the end of life. This approach to hospice care has an existential foundation based on the values and virtue-based care ethos of hospice philosophy.

Analysis part 2 - Hope and medicalisation

Death culture, and culture of care at the hospices were in different ways found to be influenced by medicalisation as we explore below.

Death culture – between two dimensions of hope

The HM’s discussion of external factors of influence on hospices revealed a tension between the two dimensions of hope. They associated the treatment culture of the referring hospitals as too focussed on hope for survival, in Marcelian terms, the concrete ‘hope that’ a treatment or cure would prolong life. The HM expressed a concern that the treatment culture did not prepare patients for the transition to hospice care but also that it was indicative that some health professionals and patients harboured

a fear of talking about death. They went on to say that to be able to talk about death required courage – a quality and virtue exercised routinely by hospice staff. As one hospice manager said: ‘They don’t have the courage to tell the patients where they are in their illness trajectory’ (Signe). The hospital system was described as lacking time and a framework for giving the message about dying to the patient and family. These comments echo the early death awareness movement’s critique of hospitals as closed awareness contexts for dying with a focus on cure rather than care (Glaser & Strauss, 1965). HM regarded what they describe as a growing trend of short admissions to hospices as a problematic consequence of this closed awareness context because it gave little time for delivering hospice care:

Signe: They (hospitals) who refer the patients to us are under such a pressure and to introduce hospice as a possibility is not something you do in two minutes. It takes time and the right framework and I simply think that [in] some places this doesn’t exist or is [not] prioritized. Then they arrive and die three hours later or after two days. And I think that we have a lot of relatives who say: “We should have been here earlier.”

Ida: I also think, oh all that we could have given them.

HM talked of the medicalisation of dying in terms of the increasing demands for medical interventions such as CVC (central venous catheters) and tube feeding to be accessed at hospices. Blood tests have become common and an increasing number of patients are referred to hospices while still receiving life prolonging treatment.

The HM acknowledged that the medicalisation of dying was not only driven by health professionals but also by patients. The HM described a user culture amongst

patients which resonates with Conrad's observation that medicalisation has become a 'consumer demand' (Conrad 2005). However, HM saw these challenges as a call for hospices to adapt. It was suggested that the 'modern hospice' ought to have the 'latitude' and 'flexibility' to provide both clinical treatment and palliative care.

Dorthe: ...we do get people with medical devices and people receiving chemotherapy or other treatments. Well, the ill person has autonomy and we have to go with that. We have to arm ourselves and be where they are, this is why I talk about latitude. (...) We have to be flexible (...) we are facing a development towards a more modern palliative care – we could choose to stay where we were and say: here is a big space for spirituality and we don't want them to come here with CVC." This was where palliative care in Denmark started 25 years ago. But we have to follow the people who choose hospices and they do it in a different way today.

The increasing medicalisation of dying was accepted pragmatically by the HM as a consequence of delivering specialised palliative care. Several HM emphasised this development as "reality" and something "we have to face". Receiving patients who are in treatment such as experimental chemotherapy, presents hospices increasingly with patients for whom concrete hopes, sustained by medical intervention, are relevant.

Jane: We cannot drive future hospices by saying: "No, we'll never give blood; we'll never measure blood pressure; we'll never give IV-medicine; (...) we'll only – or not only – we'll relieve the way we always have done no matter if the system who refers the patients, and the patients themselves require something else.

Alice: We have to be geared to have the courage to follow the ‘road to heaven’ but also to say: “and there is a different road (...) maybe there is a treatment if you are very, very lucky”.

However, this characterisation of the pressures on hospices to adapt to a new ‘reality’ was also problematised, as one manager put it: ‘I think we are challenged and I would like us to discuss that more with each other’ (Ulla).

The HM’s emphasised the value of the open-awareness of dying but also recognised that medicalised hope mediated through an increased use of medical intervention at the end of life, is the ‘language of reality’. This should be adapted to because, as they acknowledged, new possibilities for medical interventions are on the increase and patients are themselves demanding access to more treatment.

Medicalisation of a culture of care?

Though medicalisation was pragmatically accepted it was also recognised as a double-edged sword for hospice care. This was particularly evident in the HM’s discussion about evidence-based practice (EBP). The idea that research and evidence-based practice could ‘improve quality’ was mentioned in all of the interviews. However, possibility that this development could result in the instrumentalisation of care was also raised. This ambivalence between EBP drawing on a medical vocabulary and the traditional, more existential language of care was reflected in the HM’s discussion of a programme, Learning and Quality Teams (LQT) initiated by Danish Regions Clinical Quality Programme and the Danish Multi-disciplinary Cancer Group of Palliative Care in which all hospices have participated. LQT focuses on the systematic use of data from the Palliative Care Database as part of a strategy to improve the quality of life of

palliative patients as measured by various clinical tools and questionnaires. The use of such tools and the necessary adoption of clinical language were seen by some as problematic, ‘conflicting with our values’ and ‘not meaningful’, indicating a deeper tension between virtue-based care and medicalised care.

Dorthe: I think it has been very useful for us (...)

Lene: We feel that we are challenged (...) There are some working in this field who find it really hard to work with questionnaires because it provokes them like mad in their way of working: “because I want to work with people – I don’t want to work with questionnaires – I don’t want to fit people into some specific questionnaires.” Really, there is a lot of opposition against it – so it has taken a long while....

Dorthe: No discussion about that! But how does it make sense that we have to sit there and tick off boxes, and for whose sake are we doing it? Is it because somebody needs data for their data base? This is where I think we sometimes clash with hospice philosophy and some of the foundational values.

The different opinions on the LQT-project reflect tensions between an existential and medical language of care. However, the two languages were both actively operating and the dominant approach was again a pragmatic strategy. Despite reservations the HM’s felt participation in the LQT could not be denied. This was clearly expressed at one of the hospice interviews:

Else: We can’t deny LQT, we don’t think. So we make an effort to live up to it. At the same time we say: “does it make sense?” Suddenly we are supposed to implement ACP (Advance Care Planning) -conversations when the patients are

admitted. Then we look at our document for patients' life story which we haven't been good at plotting in. Then we look at the document of admission and well, if we combine the two documents, you might say we do conduct ACP-conversations.

In an interview with HM and clinical nurse specialist conducted at a hospice, they talked about some of the staff as the 'nay-sayers', referring to nurses who were critical of the LQT-project. A follow-up interview with the clinical nurse specialist gives an example that adopting a medical vocabulary was an expectation:

Susan: Some of them (the nurses) really make an effort to capture the meaning of this and think that: "well, EORTC (a measurement tool for quality of life indicators) improves my conversation with the patients when they arrive because without it I might forget an entity of symptom relief, so it helps me to make sure that I go through everything". So they will have an enthusiastic approach and positive spirit in an attempt to make it work. Then there are the nay-sayers: "yes, then we just throw this EORTC-questionnaire in the face of the patient as soon as they enter the door" (...). It might be phrased a bit harsh that the good nurses are simply capable to follow both tracks (the 'existential' and the 'evidence based') ... whereas the ones who are not on the beat find it harder.

Discussion

The findings of this study point to hospice care as directed towards different dimensions of hope pulled between an existential hope focused on meaning and a medical hope for the control of dying. As medicalisation of palliative care has been on the agenda in palliative care literature for decades, it is hardly surprising that our

findings confirm medicalisation as part of hospice reality discussed by HM as an increased use of medical interventions and language. However, the HM pragmatic but also ambivalent approach to the medical hope illustrates that the role of medicalisation within hospice palliative care calls for an ongoing discussion. As pointed out by Clark (2002) palliative care is by nature medicalised. Therefore rather than questioning *if* hospice palliative care should be medicalised we will discuss the possibility of finding a balance between medicalisation and the place for existential hope. As this study has revealed the issue of medicalisation has implications for both traditional hospice values and the culture of care. Below these aspects are discussed.

Hospice care between two dimensions of hope

A core question is whether the two dimensions of hope are incommensurable? The medical hope can be understood as death denying, clinging on to life even though death is imminent, what Bauman describes as the ambition of modernity to control and avoid death (Bauman, 1992). However, the HM advocacy for the importance of moving patients away from a medical hope towards an existential hope of meaning, is combined with their pragmatic approach to medicalisation. This points to the complexity of sustaining hope at the end of life in contemporary society. Understood through the lens of Marcel, medical hope challenges the ‘patient’ nature of existential hope which transcends the given circumstances by its reconciliation with life and death. By contrast, concrete future directed hope is exterior to the self and thus dependent on the object to which it is attached (Marcel, 1951) – for example success or failure of a treatment. As such the nature of the medical hope is fragile and risks, or is even condemned, to fail as hospice patients are by definition near to death. In other words, a sole focus on medical hope risks moving away from meaning at the end of life

and possibly encourages a ‘false’ hope for an unrealistic future as Gerrard and Wrigley (2009) observe. Inspired by Marcel, they claim that to sustain hope at the end of life involves an open awareness of fate or inevitable end as a central feature. Nevertheless, as our findings indicate, and as described in the literature the two dimensions of hope are not necessarily incommensurable. In several empirical studies of palliative care patients hope at the end of life is found to be a dynamic process between the two dimensions of hope (Benzein, Norberg & Saveman, 2001; Olsman, Leget, Duggleby, Willems, 2015; Graven & Olsen, 2018).

The HM pragmatic approach can be seen as a response to a culture in which development of medical solutions to life threatening illness is increasing, combined with a consumer culture of expectation for individual solutions. As the HM make clear medicalisation is a process not only driven by professional dominance but also by users’ demands for medical intervention. Conrad (2005:8) describes consumers as major players in an increasingly commodified healthcare system in which medical care is chosen like other products and services. As observed in a study on Canadian cancer patients, ‘medical rationalities’ from treatment culture were taken up and internalised by people who even expressed experiences of suffering in medicalised terms (Mohammed, Peter, Gestaldo, Howell, 2019). The HM pragmatic approach to sustaining demands for medical hope, places hospice in a medicalised reality to which hospice care must respond. Important here is that medical hope directed towards life-prolonging treatment or even cure, is acknowledged by HM as still relevant to hospice palliative care; however, they consider the existential hope as foundational. The raised expectations for medical hope therefore leaves hospices with the vital question: How to achieve a balance between an institutional focus on hope for treatment or prolonging life without overshadowing existential hope. The HM emphasize that at hospices they have the

‘courage’ to talk about death. By doing so they place hospice as a counter-balance to the treatment culture in which death talk can be taboo or under-prioritised. The pragmatic approach is a strategy for navigating between the two dimensions of hope.

Hospice care and language

A second challenge concerns tensions between two approaches to care and the associated language. As the findings illustrate a challenge for the culture of hospice care is the perceived need to adopt a medical language in parallel with the existential language of virtue-based care. We have discussed at some length the distinction between existential hope and medical hope, the first directed to meaning at the end of life and the second to the concrete hope for medical intervention. Both dimensions of hope are themselves nested within different cultures of care. Here we turn to the vocabularies associated with these different cultures of care articulated by HM as having a different status. Virtue-based care culture was described with words such as ‘hospice mother’, ‘values’, ‘love’, ‘compassion’, ‘altruism’ and ‘authenticity’. By contrast words such as ‘modern hospice’, ‘modern palliative care’, ‘reality’, ‘keep up with developments’ ‘professionalism’ and ‘quality’ were being used to describe a medicalised culture of care. The difference between these vocabularies points to a wider discussion of the nature of care which concerns the role and boundaries for medicalisation.

Conrad (1979) describes medicalisation not only as defining a problem in medical terms but also as an encroaching ideology which advances a particular culture of care through reductionist and quantifiable measures of human health. A medicalised approach to end of life care sets the standards by which good care is judged through such measures. In contrast, existential approaches to care have a different frame of

reference and here it is useful to draw upon the work of Martinsen. Martinsen (1998) argues that the nature of care is related to the senses because they give access to what the patient expresses, not through reflected understanding but as something pre-linguistic. On this view perceiving what the patient wants is essential for good care. As Martinsen observes, giving space for hope is ‘a work which is always relational and follows the movements of the senses in the impression and understanding of the situation’ (Martinsen, 2018, p. 99). This approach mirrors the virtue-based care and existential language emphasised by the HM as foundational for sustaining existential hope. In contrast, medical language is model- or theory-driven rather than relational. For example, a tool like the EORTC for measuring quality of life has already defined quality of life in the abstract and thus directs the carer’s gaze in a specific direction (Hansen & Tjoernhoej-Hansen, 2013). Such tools also have the potential to be reductionist if, as Glasdam, Ekstrand, Rosberg and Schaaf (2019) point out, they are used too rigidly and without attending to the person being assessed. However, the divided opinions among the HM suggest a need for both languages. Several HM conceded the benefits of using clinical tools though there was also some discomfort with the medical language as potentially damaging the virtue-based care approach. A concern we also found in our ethnographic study of Danish hospices (Graven & Timm 2019). An issue to note is that the existential language of virtue-based care and existential hope, refer to skills, methods and ‘outcomes’ which are difficult to quantify with measurable effect on quality of life, the overarching goal for palliative care (WHO 2002). Existential hope is a way of being in reconciliation with life and death. Therefore it is difficult to include in a medical language focussed on defining and solving ‘medical problems’ through such outcomes. Instead, the existential language is addressing existential hope as a response to ‘having to let go of everything’ as a HM expressed the

condition of suffering at the end of life. That the balance between an existential and medical language is being challenged in the wider field of palliative care can be illustrated by the ways in which hope has itself become a target for measurable intervention. Tools for assessing hope are being used in palliative care whereby hope becomes an ‘output’ used to identify what Paley (2014, p., 4) phrases as ‘an arbitrary range of “good outcomes” for patients.’ Below we briefly discuss the structural conditions for navigating between existential and medical hope and their associated languages.

Hope and critique

A key question is whether the ideological power of medicalisation leaves any room for existential hope and virtue-based care within the guiding ideology of hospice care? As part of the mainstream healthcare system embedded in a bio-medical model plus increased user-demands for medical solutions for managing dying, medicalisation is by nature (partly) defining the reality. This has the potential to squeeze out existential hope and the language of virtue-based care from the ideology of hospice care, an interpretation which at first glance seems to be reflected in the HM vocabulary. By relating medical hope and its associated language to ‘reality’ and ‘modernity’ the HM address a necessity of adopting a medicalised approach to the culture of care – a process in which they are also engaged. In addressing the existential language related to existential hope as foundational existential hope is ‘placed’ in a different ‘reality’ given by tradition and something ontological about human life. However, with reference to Bloch’s ideas of hope for social change as derived from dissatisfaction, this difference could point to the foundational tradition as potentially progressive and critical comments on medicalisation as constructive. Bloch’s idea is that a given historical

moment is a co-presence of elements derived from contemporary as well as past social orders (Bloch, 1977). According to Bloch, history is a repository of possibilities that are living options for future action (Kellner, 2012). In this light, critical comments about medicalisation are not necessarily voices of ‘nay-sayers’ who are not up to date with development. Rather, they can be seen as examples of a dawning consciousness of the balance tipping over in favour of a ‘modern’ medicalised care in place of hospices’ traditional focus on dying as an existential fact. Bearing in mind that almost all of the HM are nurses, the pragmatic approach could illustrate that HM lead hospices from the constraints of the nurse profession to which balancing between medicalised and virtue based approaches to care is an ongoing condition (see for example Martinsen 2018 and Brummen & Griffiths 2013). With our insight into the history of Danish hospices, we know about the battles among professions (mainly medical doctors and nurses) concerning the leadership of Danish hospices. However, this is informal knowledge and not part of our data, thus the significance is difficult to develop within the confines of this paper but would be relevant to explore further in future research.

Hope at the end of life today is still considered a mystery to be found and not solely a medical problem to be solved and hospice care has to reconcile itself to the two dimensions of hope and their respective cultures of care. Our findings indicate that there is still a role to play for hospice as a critical voice against over-medicalisation of dying in the field of palliative care as well as in society in general.

Conclusion

The study confirms our starting point for the study: that hospice care is a distinctive end of life care with a strong foundation in the values and care ethos of hospice philosophy. By using the concept of hope as a framework for exploring hospice

care we have shed light on two dimensions of hope both of which are institutionalised in hospice care: existential and medical hope. Medicalisation of hospice palliative care is a concern in several countries. Our results give an insight into how the driving engines of medicalisation work in the field of hospices as a complex of consumers demanding increased patient care options, demands for evidence-based practice and pressure for the hospice community to be drawn into a medical focus. The ambivalence of the HM's approach to medical hope described in this paper is likely to illustrate a foundational challenge for hospice palliative care which reaches further than a Danish context: How to avoid that the existential hope is overshadowed by medical hope driven by a medicalised control of dying; and how to avoid becoming isolated islands of compassionate care without use of evidence for best practice.

Acknowledgments

The authors would like to thank all of the participants in our study and the Danish Organisation of Hospice Managers for funding the study. Thank you to Simon Woods for comments on an earlier draft.

References

- Ariès, P. (1981). *The Hour of Our Death*. Oxford: Oxford University Press.
- Bauman, Z. (1992). *Mortality, Immortality & Other Life Strategies*. Cambridge. Polity Press.
- Benzein, E., Norberg, E. & Saveman, B.I. (2001). The meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliative Medicine*, 15(2),117-126.

- Bloch, E. (1959/1986). *The Principle of Hope*. Vol. 1-3. Cambridge: MIT Press.
- Bradshaw, A. (1996). The Spiritual Dimension of Hospice: The Secularisation of an Ideal. *Social Science & Medicine*, 43(3), 409–419.
- van Brummen, B. & Griffith, L. (2013). Working in a medicalised world: the experiences of palliative care nurse specialists and midwives. *International Journal of Palliative Nursing*, 19(2), 85-91.
- Conrad, P. (2005). The Shifting Engines of Medicalization. *Journal of Health and Social Behavior*, 46(1), 3-14.
- Conrad, P. (1992). Medicalization and Social Control. *Annual Review of Sociology*, 18, 209-232.
- Clark, D. (2018). *Cicely Saunders. A Life and Legacy*. Oxford: Oxford University Press.
- Clark, D. (2016). *To Comfort Always. A history of palliative medicine since the nineteenth century*. Oxford: Oxford University Press.
- Clark, D. (2002). Between hope and acceptance: the medicalisation of dying. *British Medical Journal* 324(7244): 905–907.
- Clark, D., & Seymour, J. (1999). *Reflections on palliative care*. Buckingham, England: Open University Press.
- Danish Health Authorities (2017). *Anbefalinger for den Palliative Indsats [Recommendations for Palliative Care]*. Retrieved from: https://www.sst.dk/da/sygdom-og-behandling/~/_media/79CB83AB4DF74C80837BAAAD55347D0D.ashx

DMCG-pal (2017) National criteria for admission for specialised palliative care.

Retrieved from

<http://www.dmcgpal.dk/files/visitation/natvisitationskriteriernov2017.pdf>

Feifel, Herman (ed.) (1959): *The Meaning of Death*. New York: McGraw-Hill.

Floriani CA & Schramm FR (2012). “Routinization and medicalization of palliative care: losses, gains and challenges”. *Palliative and Supportive Care* 10(4), 295–303.

Garrard, E. & Wrigley, A. (2009). Hope and terminal illness: False hope versus absolute hope. *Clinical Ethics*, 4(1), 38-43.

Glasdam, S.; Ekstrand, F. Rosberg, M., van der Schaaf, AM (2019). A gap between the philosophy and the practice of palliative healthcare: sociological perspectives on the practice of nurses in specialised palliative homecare. *Medicine, Health Care and Philosophy*. Published online ahead publication. Retrieved from: DOI <https://doi.org/10.1007/s11019-019-09918-2>

Glaser, Barney & Strauss, Anselm L. (1965). *Awareness of Dying*. Chicago: Aldine.

Graven, V. & Olsen, J.B. (2018). *Hvor der er håb. Fra teori til sundhedsfaglig praksis*. (Where there is Hope. From theory to healthcare-professional practice). Copenhagen: Samfundslitteratur.

Graven, V & Timm, H.U. (2019). *Hospice Philosophy in Practice: Toward an Authentic Death*, Published online ahead publication: *Omega: Journal of Death and Dying*. Retrieved from DOI: <https://doi.org/10.1177/0030222819852850>

Graven, V. P., & Timm, H.U. (2017). *Hospice 25 aar i Danmark: Hvilken forskning findes der?* [Hospice, 25 years in Denmark: existent research?] Omsorg. Nordisk

Tidskrift for Palliativ Medisin, 34(4), 61–69.

Hansen, H. P., & Tjoernhoej-Hansen, T. (2013). In who, how, and what? Quality of life psychosocial cancer research. In. N. Warren & L. Manderson (Eds.), *Reframing disability and quality of life: A global perspective* (pp. 79–95). New York, NY: Springer.

Hansen, M.B, Andersen, M, Groenvold, M. (2019). Danish Palliative Database, Annual Report. Retrieved from DMCG-PAL homepage:

http://www.dmcgpall.dk/files/aarsrapporter/24_06_19_aarsrapport_dpd_2018_med_3_reglen.pdf

Hospicemanagers.dk. *Organisation of Hospice Managers in Denmark*. Retrieved from:

<http://www.hospicelederforening.dk/>

James, N. & Field, D. (1992): The Routinisation of Hospice: Charisma and Bureaucratisation. *Social Science & Medicine*, 34(12), 1363–1375.

Kearney, M. (1992): Palliative Medicine – just another specialty? *Palliative Medicine*, 6(1), 39–46.

Kellner, D. (2012): Ernst Bloch, Utopia and Ideology Critique, in P. Vieira & M. Marder (eds.): *Existential Utopia – New Perspectives on Utopian Thought*. London: Continuum.

Kübler-Ross, Elizabeth (1969): *On Death and Dying*. New York: Macmillan.

Kvale, S. & Brinkmann, S. (2009). *Interviews: Learning the craft of qualitative research interviewing* (2nd ed.). London, England: SAGE.

Marcel, G. (1951). *Homo Viator. Introduction to a Metaphysic of Hope*. London: Victor Gollancz.

Martinsen, K. (2018). *Bevegelig Berørt. [Susceptible Moved]*. Bergen: Fagbokforlaget.

Martinsen, K. (1998). *Fænomenologi og omsorg. Tre dialoger med efterord af Katie Eriksson. [Phenomenology and care. Three dialogues with epilogue by Katie Erikson]*. Copenhagen: Gads Forlag.

McNamara, Beverly (2004). Good enough death: autonomy and choice in Australian palliative care. *Social Science & Medicine*, 58(12), 929–938.

Ministry of Health. (2017). *Healthcare in Denmark - An overview*. Retrieved from [https:// www.sum.dk/English//media/Filer%20-%20Publikationer_i_pdf/2016/Healthcarein-dk-16-dec/Healthcare-english-V16-dec.ashx](https://www.sum.dk/English//media/Filer%20-%20Publikationer_i_pdf/2016/Healthcarein-dk-16-dec/Healthcare-english-V16-dec.ashx)

Mohammed, S. Peter, E., Gestaldo, D., Howell, D. (2019). The medicalisation of the dying self: The search for life extension in advanced cancer. *Nursing Inquiry* Published online ahead publication. Retrieved from DOI: <https://doi.org/10.1111/nin.12316>

Morgan, D.L. (1996). Focus Groups. *Annual Review of Sociology*. 22,129-52.

Olsman, E., Leget, C. Duggleby, W, Willems, D. (2015). A singing choir: Understanding the dynamics of hope, hopelessness, and despair in palliative care patients. A longitudinal qualitative study. *Palliative and Supportive Care*, 13, 1643-1650.

Payley, J. (2014). Hope, positive illusions and palliative rehabilitation. *Progress in Palliative Care*. 22(6), 358-362.

Robinson, J., Gott, M., Gardiner, C., Ingleton, C. (2017). Specialist palliative care nursing and the philosophy of palliative care: a critical discussion. *International Journal of Palliative Nursing*, 23(7), 352-358.

Saunders, C. (2005). *Watch with me. Inspiration for a life in hospice care*. Lancaster: Observatory Publications.

Saunders, C. (1961). *And from sudden death*. In Cicely Saunders - Selected Writings 1958-2004.

ten Have, H. & Clark, D. (2002). *The Ethics of Palliative Care. European Perspectives*. Buckingham: Open University Press.

Seale, C.F. (1989). What happens in hospices: A review of research evidence. *Social Science & Medicine*, 28(6), 551-559.

Timm, H. (2014). *Historien om palliation i Danmark – mangler at blive skrevet*. [History of palliative care in Denmark – needs to be written]. *Omsorg: Nordisk Tidsskrift for Palliativ Medisin*, 31(3), 15–19.

Van Manen (1990). *Researching Lived Experience*. London, Ontario, Canada. State University of New York Press.

WHO (2002). WHO Definition of Palliative Care. Retrieved from:
<http://www.who.int/cancer/palliative/definition/en/>

Woods, S. (2007). *Death's dominion: Ethics at the end of life*. Maidenhead, England: McGraw-Hill Education, Open University Press.