

Biographical Research at the Boundary: A Careful Listening for the Micro, Meso, and Macro in End-of-Life Care

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Abstract

Death is an intrinsic part of the ecology of life. Yet in Western societies, end-of-life care has to a large degree moved out of the home and into institutions. A pressing question for educational institutions and employing healthcare organizations is how to train for and facilitate quality and resilience among those working at the boundary between life and death. Any such endeavor must rest on knowledge about how encounters with the death of others inform the self-understanding and praxis of end-of-life care professionals.

Applying a biographical narrative approach to the narrative accounts of healthcare workers from palliative care and intensive care units, the chapter undertakes a careful reading of free-associative narratives, in order to elicit the entangled relation between the subject and his or her contexts, past and present. The chapter is thus an empirically based exploration of how the individual's fear of death (micro), organizational feeling rules (meso), and societal discourse (macro) simultaneously and mutually inform the life and narrative of the end-of-life care professionals.

Keywords

death – end-of-life care – biography – free-associative telling – discourse

1 Introduction

In the ecology of life, death plays an undeniable and significant part. However, the context of death and dying has changed to a large degree in Western societies, as the initiative for care of the dying is passed from community, family, and friends to welfare institutions. Today, for most people the process of dying, and the actual moment of death, take place in hospitals, nursing homes, and

hospices. End-of-life care has become a discipline within mainstream medicine and is thus predominantly the focus of professionals who deal with death as part of their work (Ariès, 1976).

This major cultural change raises pressing questions relevant to the field of adult education, one of which is how to prepare and support health professionals working in end-of-life care. As a hospital chaplain and teacher at a university offering education for both future and current health-care professionals, I can testify to the relevance and legitimacy of this question. In order to address it, we need empirically based knowledge about how this major cultural shift in the care of the dying influences both the experiences of end-of-life care professionals and the socially constructed languages (discourses) within which their experiences and narratives are embedded.

In the following, I will present one such endeavor in which a biographical narrative interpretive approach is applied in order to help elicit the relations between the societal (macro), institutional (meso), and individual (micro) in the narrative accounts of end-of-life care professionals – physicians, nurses, and hospital chaplains from palliative and intensive-care departments in Norway and the US. The rationale, philosophical underpinnings, findings, and theoretical discussions of the study are presented more comprehensively elsewhere (Moen, 2018). In line with the aim of this book, focus on the following is methodological – on how a biographical approach can make for contextual reading of the personal in the professional.

2 Allowing for Free-Associative Telling

A premise for the study is that when asked to reflect on ourselves or another, we often respond to the question of self by telling stories (Ricoeur, 1988). There is no difference in the case of health-care professionals. Yet, as self-understanding is not only expressed by what is said, but also how it is said, it takes careful listening to both the explicit and implicit, to omissions, contradictions and paradoxes, in order to identify self-understanding – the thin sense of subjectivity, the subject's characteristic way of receiving and organizing experience – making itself evident in the telling.

In order to remain open to other contexts in life being as, or even more, influential to the health professional than what is taking place at the bedside of the dying patient, it was important to let the invitation to tell be open enough so that the professionals could narrate life both from inside the clinic and beyond. Hence, a carefully designed invitation to induce a free-associative telling was as

important as the later careful reading of it. Leaning on Biographical Narrative Interpretive Method (BNIM) (Wengraf, 2001), which insists on the uninterrupted telling of stories, only a single question was offered to the participants:

As you know, I am interested in how health professionals as persons have changed, or not changed, due to working with terminally ill and dying patients. Therefore, can you please tell me your life story: all those events and experiences, which were important for you personally? Please take the time you need! I will just listen and won't interrupt you with questions. I will just take notes so that I can remember what I want to ask you about when you have finished telling me about it all. Take the time you need. Start wherever you like.

Dina, the palliative care physician, finished her first narrative after 35 minutes. Jacob, the intensive care physician, shared over 30 clinical incidents and spoke uninterrupted for two hours, while the other participants placed themselves somewhere in between. After the first un-interrupted telling there was a second session, in which I asked follow-up questions, committing to the sequence and language of the first narrative they had shared.

3 A Contextual Reading

Most participants included stories from both inside and outside the clinic. In the next paragraphs, the cases of Fiona, Eric, Dina and Herbert will serve to illustrate how a biographical approach allows for identification of how experiences outside the clinic may inform the professionals' self-understanding and impact their practice of care.

Fiona, an anesthesiologist, working in an ICU for children, very much centers her account on questions pertaining to her choice of occupation. However, she spends the first part of her account talking about how she grew up with "a steady flow of illness and death in the family", including the death of her own father when she was a toddler, and subsequently those of her grandparents and aunt. They all stayed in her home during their terminal phase. At one point, somebody even made the comment, "Gee, you are really growing up in a hospice". As an eight to nine year-old, it left her "afraid that all around me would die".

The presence of death combined with growing up with a partly non-present mother who, as a nurse, served as "the health department for the entire family",

triggered strong ambivalent feelings towards healthcare: “Not something I wanted by any means ... sick people was the worst I could think of. They were everywhere and took too much time”. The impatience with the sick back then may resonate in her encounters with dying patients’ relatives who, here and now, rage against the injustice implied in their beloved facing death: “How can this happen to me and mine?” The physician must temper herself in order not to exclaim, “How in the name of heaven could you believe it couldn’t happen to you?”

As a coping strategy in relation to her fear of those around her dying, Fiona, looking back on her life, states that she “wanted to fix most things”. This desire seems to linger with her and inform her choice of pursuing critical and intensive care and the desire to master “special and difficult patients”. At one point, she even makes the statement: “Being a physician, doing intensive medicine, is a way of saving my own psyche”. Yet, she concludes that ending up in end-of-life care is “a coincidence”, and thus she seems to be overlooking obvious clues in her biographical account, which, to the researcher at least, make her choice of vocation, and lack of patience with certain relatives, more comprehensible if not less paradoxical.

Herbert, an expert in palliative care, is similarly paradoxical, considering his biography. He tells about his anger related to how the life of his family of origin revolved around his mother’s continuous complaints about her pain and sickness as he was growing up. According to Herbert, she was “too absorbed in her pain”. The anger was particularly related to how this limited the life of his father. Yet, in his early clinical assignments, Herbert is, according to his own account, paradoxically, particularly drawn towards patients with pain issues: “I began to collect a group of patients that nobody wanted, they tended to have chronic pain”.

A related paradox, not mentioned in his account, is related to him growing up in a context dealing with pain, emotions, and intimacy in a “stoic” manner: “To me personally it felt awkward to say something consoling, encouraging ... in our family we just didn’t know how to react to that stuff”. In his present marriage, he says he still finds it hard to be emotionally transparent. Yet, in his professional life he explicitly treasures the intimacy by the deathbed, as it is “those interactions with patients where we ‘touch’ each other that really get to me ... It fills my vessels back up to have those relationships”.

Dina is a disconfirming case in that she almost steers clear of clinical experiences in her narrative. This physician has dedicated her professional life to the well-being of terminally ill and dying patients. Such a life, one may expect, would bring forth stories about life-changing encounters at the boundary between life and death. Yet, there is another selective principle for her account, for what is included, and what she leaves out.

What “first comes to mind”, when Dina is invited to share the experiences most significant to her, is an emancipation process from oppressive religiosity. The quest for freedom, opposition towards any confining structure, as well as the importance of speaking one’s mind, run like red threads throughout her narrative account, as she repeatedly speaks about herself in terms of “always” having been a seeker and speaker of truth. She regards being a notorious truth-seeker her most characteristic trait, one she relates to being a truth-speaker. Dina relates the urgency she felt to speak truth to an upbringing with too many lies and double standards. “[I am] never going to tell another lie in my life”. This “ability” to be “open and direct”, she “use[s] it a lot” in her work, even though, at times, it feels like “breaking through a wall in order for people to understand stuff”.

Even though it is a concern that originated outside the clinic, the urge to be a truth-speaker informs Dina’s encounters with dying patients and their families within it. In this, she sees herself as parting not only from those she regards as hypocrites in her faith community of origin, but also current colleagues who are scared of talking about death and dying.

The concern for truth-speaking eventually brings her narrative to the bedside of a terminally ill and dying patient, and fierce accusations from relatives that her truth-speaking about imminent death was neither called for nor welcomed. This could be a legitimate response on the part of the relatives, as it should largely be the patient’s call to decide how and when matters of ultimate concerns are to be communicated. At the same time, the response may also speak of a more general uneasiness with death in the culture – a conspiracy of silence – I will explore this further in the last part of the chapter.

The fact that Dina, Fiona, and Herbert did not make links between their contexts of upbringing and choice of vocation may simply relate to the fact that all human beings are limited to a first-person perspective. It takes somebody else’s careful listening for omissions, paradoxes, and contradictions to identify links and tensions between different parts of a biographical account. This is no less true when considering the notion of “the defended subject”.

4 Exploring Individual and Social Defense

In the second session of Biographical Narrative Interpretive Method (BNIM), immediately following the first, the researcher commits to the wording and sequence of the initial account but invites the narrator through open invitation to get beyond the rehearsed narratives and closer to marginalized experiences. These may be events and experiences that have become defended parts

of the biography, but which may be of key importance when trying to understand why this life is told this way. As in Anne's case, it may take several nudges before the interviewee is comfortable visiting more challenging parts of her life and story:

When I worked at the other unit there was a man who was dying, and we had someone attending to him at all times. I remember I got in there and he had such a frantic anxiety in the eyes, horrible anxiety. I was afraid, really, and then I ran out to grab a drink and when I came back, he was dead. That I struggled with ... in hindsight, I could say almost that I ran out to grab the drink to get out of there. It was like vicarious, right. That I struggled with for a while. I remember I had to sleep with the light on afterwards. I was a brand-new nurse.

Stories that haunt health-care professionals (Rashotte, 2005) may have originated 30 years ago, as in Anne's case, but still continue to carry shame and guilt. Situations that "stick" thus have the potential to inform both the self-understanding and practice of the professional throughout his or her career. It takes another's capacity "to contain" (Bion, 1962) painful and shameful experiences in order to turn them into sources of life-long learning for the professional. Hence, a pressing question, crucial for Anne, is whether the angst in relation to her own finitude, against which she defends herself, resonates with a social defense (Menziés-Lyth, 1960) against the same basic condition established in her professional context.

Glaser and Strauss's (1965) classic grounded theory study from hospitals in the US identified that hospital units collude in varying degrees in "conspiracies of silence" in regard to death, holding back information or providing wrong information to the patient, in order to prevent awareness that death is at hand: "The patient does not recognize his impending death even though the hospital personnel have the information" (p. 29).

Jacob, the ICU physician, shares an encounter in which he is more knowledgeable about the imminence of death than the dying patient: "[I] remember one of the days before he died he took me by the hand and kind of ... felt that 'we are going to overcome this' ... and ... deep inside I knew already at that point that he is not going to make it". Herbert, similarly reflecting on an encounter with a young man who passed away just a couple of days prior to the interview, questions himself: "Did I fulfill my role? Was I honest enough? Did I short-change him in any way?"

At times, according to the participants in this study, it is patients who do not want to know, and relatives who do not want to disclose, as in Dina's case,

which implies an expectation of holding back information, which can have a detrimental impact on staff (Noble, Nelson, & Finlay, 2008).

An ontology of defended subjectivity – philosophical (Heidegger, 2002) and psychoanalytical (Klein, 1959) underpinnings for, and possible methodological implications of (Hollway & Jefferson, 2000) – are accounted for in another book (Moen, 2018). Suffice it to say here that the shared existential burden implied in finitude and death is something we defend ourselves against, both as individuals (micro), groups (meso), and societies (macro) (Becker, 1973; Yalom, 2008).

Repression can serve a purpose, make life manageable, a “strange power of living in the moment and ignoring and forgetting” (Becker, 1973, p. 23), enabling the forward momentum of activity without which people may suffer psychotic breaks. Hence, we need to be tolerant of the fact that we deal with death differently. Yet, it is of existential and ethical importance, relevant to the quality of healthcare, that health professionals are willing and able to address it when called to do so. Awareness of death can keep end-of-life care professionals from unnecessary and unethical treatment, which may bring prolonged suffering to patients and moral stress to themselves.

The above considered, research methods are called for that can identify how the death of patients triggers a defensive stand in health professionals in ways that may have a profound impact on patient care. Allowing for free-associative, non-directed telling is one methodological answer to such a call. An uninterrupted telling of stories, in which the narrator gets to “choose what to tell and how to tell it” (Charmaz, 2006, p. 27), may reveal rehearsed stories and manners of speaking, but also omissions, contradictions, and paradoxes that leave hints of what is beneath the surface.

We have seen how “feeling rules” (Hochschild, 2003) residing in the contexts of the professional (meso) may inform the experience of end-of-life care. Not all of these socially constructed and agreed-upon discursive manners of speaking (Bourdieu, 1977), or not speaking, about death originate within the clinic or healthcare system though; some are shared and implicit in the culture as a whole (macro), which is where we will turn next.

5 Investigating Discourse

Eric, a chaplain in a palliative care context, finds that his experience of death contrasts profoundly with what is experienced by people outside the clinic, and that him being more at ease with death represents something “peculiar” for them, and leaves him with a sense of being different. Whenever he conveys

to those who ask that “it is not so bad and difficult” to work with death and dying, he is left with the feeling that they think: “It can’t be right, it is not possible to state things like that”.

Carl, also a chaplain, once took it upon himself to facilitate a gathering around the open coffin of one of his own family members: “[I] was told afterwards that it was a little too much ... it wasn’t totally okay”. He recognized his former attitude to death in that of the other family members: “They were in the same situation as me when I was young”.

Gail expresses a similar sense of being different: “When people ask me ‘how do you work with dying children’ ... I want to say I enjoy being with people during the death process That’s a weird thing, you can’t say that to anybody who is not a chaplain”.

Considering the marginalization of death in Western society – how it is institutionalized and thus out of sight – it makes sense that there is something strange, perhaps even repulsive and “tainted” (Kessler et al., 2012) about professional end-of-life care. The interviewees’ articulation of their “natural” relation to death is uttered in a society in which death is “forbidden”, if we follow the argument of the French historian Phillipe Ariès (1976, p. 85), and thus anything but natural, potentially even a provocation. The end-of-life-care professional thus represents a “discredited attribute” in the ecology of life and, as such, he or she may be regarded as a social anomaly (Douglas, 2002).

Working with death and dying in a society in which death is “forbidden”, thus informs the experience and self-understanding of the professional. Even though most participants conveyed similar thoughts, feelings of resembling a social anomaly seem to resonate more strongly with those in palliative care than in intensive care. Perhaps because most people associate the latter with saving lives to a greater degree than facilitating preparation for death.

Herbert and Jacob, both physicians in end-of-life care, question colleagues who refuse to acknowledge the inevitability of death, and who continue to treat the dying patient as if he or she will survive. Both expressed indignation when the belief in treatment represented a “triumph of fantasy over reality” (Levine, 2013, p. 94). Nevertheless, both had to acknowledge being caught in the same dynamics, as they also continually encounter the expectations and demands of co-workers, employers, patients, and relatives to protect the notion that death can be prevented – even when it is clearly impending. For example, in one case, Jacob and a colleague decided to stop resuscitation, and the patient’s son “got furious because we had given up on his father and he jumped onto the bed and continued resuscitation”.

The above may be illustrative of how in a secular age (Taylor, 2007), following the decline of meta-narratives – religious and political – there is no shared

discourse on death and dying. Nothing resembling the “*Ars moriendi*” (Ariès, 1976, p. 34) – the culturally shared, and very much religiously informed, ways of referring to the meaning of death in the Middle Ages and later. Rather, in the current situation, there are several discourses which may compete with one another – treatment philosophies, like palliative care (Leget, 2007) and the principle of autonomy (Beauchamp & Childress, 2013), but also organizational models, like New Public Management (Hood, 2015), and finally health-care jurisdictions.

In the final part of this chapter, we will undertake a careful reading of Jacob’s account, in order to show how a biographical approach may allow for the identification not only of dominant discourses (macro), but also how they may be related to, and enhanced by, personal experience (micro). One such link is made manifest in Jacob’s repeated talk about the importance of “being professional”:

But anyway our unit is very professional, I think. It is important to behave in an orderly manner, be professional, that is what I think. That is a very important message ... we have to act professionally ... and do what we are supposed to in a way without mixing in too many emotions and feelings.

This, according to Jacob, is a message he makes an effort to “convey to other colleagues”, thus eliciting the interrelatedness between micro and meso. He then moves on to elaborate what he understands “professional” to imply in different clinical situations: when communicating a request for autopsy, when giving out information, when responding to requests for documents from relatives, when responding to the same requests from authorities.

What is common to all these situations is that they are regulated by law. Hence, Jacob is implicitly making a case for the importance of staying on the right side of the line between professional conduct and misconduct. The degree of regulation, and thus the risk of legal consequences, increases with every new typical situation he mentions. Eventually, the free-associative telling takes Jacob to an unpleasant memory, which perhaps explains the reason for his focus on this issue:

[I] have had unnatural deaths that have been reported to the police, and reported to the health authorities, and then a file is opened and ... one has to give out all the documents of course ... one possibly gets a feedback that something is blameworthy. One can get a warning. That sort of thing one must be prepared for ... one gets hung up on details ... so it is very important to be orderly when it comes to such journal notes.

The methodological point to be made is that merely recording a memo about Jacob's concern with behaving in a professional manner and adding it to similar utterances in other cases, leaving the individual case unexplored, would miss a deeper understanding. On the other hand, "being faithful to the unique histories, circumstances, and meanings" (Hollway, 2013, p. 99) by taking Jacob's biography into account, not only provides insights but also explains why "being professional" is so important to him.

Another link between discourse (macro) and the psychic (micro) is identified when Jacob tells about how he suffered "soldier's heart" – chest pain without any identification of heart failure – a few months prior to the interview. He relates the incident to the "violent organizational change" that was taking place at his hospital: "You are sucked in and whirled around with it, it never stops ... feels life threatening". The focus is on making services profitable, which is stressful according to Jacob, and the dilemmas are felt in particular when "playing musical chairs" regarding who, among the patients, are to be prioritized at the intensive care unit in which he is head physician.

Jacob is thus explicating what other participants also report, and what is echoed in the literature (Hood, 2015); namely, the stress felt related to New Public Management, which has been the organizational model in Norway and other countries since the early nineties. A major critique is that professional and ethical concerns are subject to managerial imperatives. It is this, more than the demands of encountering death and dying on a daily basis, which evokes stress, according to Gail: "The death and dying is not driving me away. I want to stress that health-care politics really sealed the deal for me". Retiring early, because she does not want "to die in my job" due to "the rat race" – the ever-increasing expectation that one must do more in less time.

6 Concluding Remarks

The accounts of Jacob and Gail echo a concern, evident in the literature, about a lack of recognition for the welfare professional as an experiencing subject (Froggett, 2002; Clarke et al., 2008). In professional contexts marked by rapid change, technological development, demands for efficiency, and profitability, it is critical to make space for personal testimonies. Allowing for narratives through open invitation, a free-associative telling and a careful reading is one way of re-humanizing, and thus it is an essential, ethical, and ontological necessity to counter de-personalizing tendencies in both healthcare and research.

Another gift of biographical narrative research is that it provides "thick" descriptions (Geertz, 1973) – rich contextual data marked by "detail, complexity

and contradiction” (Braun & Clarke, 2013, p. 24). Hence, it provides in-depth knowledge about complex human beings and reduces the possibility of oversimplification and one-dimensionality that can take place when “reducing complexity to single scores” (Hollway & Jefferson, 2013, p. 101). It allows one to elicit how the ecology of the life of the individual must be understood in context (micro, meso, and macro), as “the given uniqueness of every voice” (Cavarero, 2005) is interwoven with “the universe of the undisputed” (Bourdieu, 1977, p. 18) – contextual manners of being and speaking both past and present, local and global.

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