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Narratives and communication in health care practice

What competences are relevant for tomorrow´s health care professionals to communicate about illness, life and death?

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Abstract

The article concerns the issue: How to deal with the increasing challenges of communication in the health care sector? On the one hand, it focuses on how to include the patient's and relatives´ perspectives. On the other hand, it focuses on the existential/spiritual perspective which is now included in various official visions papers and recommendations. The main question is pedagogical: How do practitioners in the health sector i.e. in nursing deal with these perspectives? The materials are the Danish Health Board´s program of rehabilitation and palliative care, data from a focus group study, and data from published autobiographies. The analysis shows that challenges are centered on communication about existential and spiritual matters. The relationship between being professional, personal and private is focused on in the light of the concepts of empathy and epoché as well as in a discussion of a phenomenological approach. Finally, a teaching practice dealing with the challenges is outlined seeing education as an existential and relational activity.

Keywords health care, narratives, phenomenology, existential, communication

Introduction

A wave is currently washing across the world. Qualitative health research is discussed in books, in journals and at conferences. The discussion is part of both an international and various national agendas, focusing on the political, the scientific, and the ethical and practical challenges within contemporary health care services. In the years to come a global challenge is to reorganize the health care service with the purpose of engaging the population in health promotion and the purpose of making individuals and groups co-constructors of health and well-being (Aldridge, 2004). This article is based on impressions gained by attending conferences in the U.S., Canada, Europe and Denmark in 2012-14[2]. In Denmark in 2012, a local challenge came up as the National Health Board presented a new program for rehabilitation and palliative care as part of a general cancer treatment plan[3]. In this program the bio-psycho-social model includes an existential/spiritual perspective, and the program focuses on the resources of patients and relatives. The Health Board estimates that counseling and support should be part of ordinary communication and dialogue between patients, professionals and relatives for 70% of patients living with a cancer-diagnosis; 25% of patients will need a professionally led effort, and 5% will need a special effort. It is stated that counseling can also be provided as part of educating patients individually or in groups. This means that communication on these topics is to be part of practice for health care professionals dealing with cancer treatment, not only for "experts" such as priests or psychologists as has been the practice.

Multiple perspectives are to be considered and multiple voices are to be heard, resulting in challenges for health care practice as well as for qualitative health research. Research and published narratives about illness, especially narratives about being a cancer patient, indicate that a cancer diagnosis often incites questions of an existential nature. Existential and spiritual topics may not be new in a health care context, but the official requirement that professionals are able to communicate about these matters is new. To elucidate challenges related to this kind of communication as well as the challenges concerning multivoicedness I want to illustrate how narratives (i.e. autobiographies) and creative approaches (i.e. arts) can be part of future practice in educating health care professionals. This means a practical focus concerning communication and a theoretical focus concerning a renewed phenomenological approach.

Since 2000 a veritable wave of autobiographies of illness experiences swept across the entire Western world. In *Läkertidningen*, the Swedish equivalent of the *American Journal of Clinical Medicine,* the development of this genre is described as a result of the development of a more independent patient role and a focus on the patient´s perspective.The perspective now includes relatives, which leads to an examination of how to deal with multivoicedness. The genre fulfills an important function in modern man's search for answers to what remains unanswered in the case of illness: "Why was I struck by illness? Do my illness and my suffering make any sense? How do I live with a chronic illness?" (Häggblom and Mattsson, 2007, my translation). Apparently, people want to share narratives about illness and these reports seem to have an audience. What might explain the interest is that some experiences are not articulated or processed adequately within the health care system together with the fact that the publishing boom happened at the same time as a considerable activity in various patient organizations was going on. Experiences about being ill are also shared as e-communication and the number of private blogs on the internet increases day by day.

In the period from 2000 until now there has been an intensive focus on developing communication skills within the community of health care professionals. The Calgary-Cambridge guide has become a widespread model all over Europe for developing skills for communicating with patients in medicine (Silverman, 2005). Books using the model were published in Denmark (Carlsson and Ege, 2010; Christensen et al., 2011), and since 2010 a communication program based on the guide was conducted at a large regional hospital involving all employees with patient contact (Ammentorp et al., 2014). The model consists of 71 topics that may be supportive for the doctor conducting a consultation, and students are trained in labs often with actors simulating being patients. The model guides the medical interview, and some focus is on the human side of medicine, i.e. the patient's perspective as well as on the doctor showing empathy. Yet, I shall argue why this model is not adequate for what we are dealing with here: communication about existential and spiritual matters. First of all, the medical interview aims at providing strategies for intervention based on a diagnosis; here our aim is understanding or examining narratives expressing the experience of illness (or of dying).

Communication in medical education is often detached from the medical content, and students do not perceive communication as a key part of their clinical learning; they rather perceive communication lessons as an add-on. This is the problem the Calgary-Cambridge guide is meant to solve, but this change may take years (Silverman, 2009). This is probably also the case in the learning practice of the nursing profession. I want to zoom in on practice and training, to show how autobiographies and arts can be put into play in teaching concerning communication. The lack of a precise language concerning existential and spiritual matters is a barrier to developing the dialogue; we are at the very beginning of developing a language suitable for this purpose. I return to this theme later, but first I introduce voices of professionals and voices of patients.

Voices of professionals

Teaching communication on a special course for nurses working with cancer patients, I asked these professionals (newly qualified as well as experienced nurses) about problems concerning communication with patients and their relatives. They listed these issues:

> How can I perceive the unspoken, tacit knowledge which is often the most important information on how patients and caregivers perceive the distressing experiences of being ill?
>
> What do I do when the conversation takes an unexpected turn?
>
> How do I communicate about hope?
>
> How can I become aware of what I am actually doing in a difficult situation or conversation?
>
> How can I use the theory of narratives in practice?

No existing models of communication strategy seem to neither solve these challenges nor give adequate answers to these questions. As this was a special course and some of the participants were experienced nurses, they referred to a number of communication techniques that they had met during their training. It was almost a tour de force through various models – as if models constantly change as fashions do – and it seemed as if professionals constantly are seeking for a new recipe, a new tool or technique to solve the problems. Nowadays the word "skill" seems to be the keyword to what is asked for (Silverman, 2005; Deurzen and Adams, 2011). When asked what the nurses need to acquire the necessary skills, they stated:

> I need more theory to give my answers a safe basis
>
> I need more "techniques" to communicate with the patient and understand his/her life world
>
> I need specific tools or skills for practical use in conversations about being ill and in conversations about life and death

Let us have a closer look into some of these statements, first, about tacit knowledge and about using the theory of narratives in practice; later, about more theory and techniques for practical use. Embedded in tacit knowledge as well as in expressing experiences through narratives is the concept of empathy. Usually empathy is described by the statement: ´being able to put oneself in someone else´s shoes and be able to feel what they feel´. Though, we know it is not possible to do so. We know from neuroscience about mirror neurons as neural basis for the capacity of developing emotions such as empathy (Hart, 2007) and we know from psychology about developing the ability for mentalization, which involves both a self-reflective component as well as an interpersonal component (Fonagy et al., 2002). This serves as a basis for working with refining the capability of empathy together with the capability of reflecting on and communicating about the needs related to existential and spiritual matters.

Voices of patients

I focus on the genre autobiography for several reasons. First, the genre has a similarity to the interview, a well-known method in qualitative inquiry, and yet it is different because the author is presenting a lived experience description that the reader can reflect on and engage in. Second, the fact that the patient is situated in a cultural, historical and relational context and is focusing on the influence of illness in everyday life qualifies the autobiography as research data and as training material.Third, autobiographies telling stories about illness have been published all over the Western world which opens up the discussion of a cultural perspective. Here I concentrate on three autobiographies published in Denmark[4], selected by their significant titles illustrating the point: the usefulness as material in a training setting by putting into words extremely difficult situations and emotions. *No Man´s Land* (2009) is narrated by a mother who lost her daughter to leukemia – describing the time at the hospital as being in a no man´s land and later on describing the process of grieving. *The Waiting Room* (2011) is a dialogue between a nurse and a man in his thirties, dying of cancer, leaving behind a young wife and a small child. The dialogue focuses on existential and spiritual issues concerning life and death. In *The Taboo Breaker* (2011) two sisters both diagnosed with breast cancer comment on various taboos related to being ill. During the period of illness they showed their bald heads and they ask: Why is a cancer patient supposed to wear a wig? A possible answer is that perhaps it for the sake of the healthy, not to be confronted with illness.

In all three narratives the experience of being in a special area is described, although we know many people have experienced illness. Also situations difficult to handle both as a patient and as a relative are described, and they all comment on the role of health care professionals. Most patients have had positive experiences with professionals as individuals, but the health care system as such seems to be lacking the ´ability´ for empathy and adequate communication. This means there is a challenge at an institutional level as well as at an individual level. As mentioned, custom has been to call the expert, i.e. the priest or the psychologist, if a patient or relative wants to talk about spiritual or existential issues. That is, these issues are understood in a religious or a therapeutic context, but as nurses are also expected to communicate about and take into consideration an existential/spiritual perspective, it is necessary to develop ways to work with these issues in a secular world, not automatically using or referring to neither a religious language nor a therapeutic one. Let us turn to contemporary theory of phenomenology to see if there is any help to answer the questions asked by the professionals above.

A renewed discussion of a phenomenological approach

Amongst a variety of phenomenology I focus on a pedagogical approach. Max van Manen emphasizes in *Phenomenology of Practice* (2014) that a phenomenological approach is not a method, not a technique nor a tool. A phenomenological approach is a path or a way to understanding. To get to the heart of an experience, van Manen focuses on wonder, openness, concreteness and approach as part of the process of epoché and reduction. The goal is to gain access to the pre-reflective experience and "The "way" to knowledge and understanding begins in wonder" (van Manen, 2014, p. 223). In this process the most important act – epoché - is to put into brackets assumptions, presumptions, common understandings, and scientific explanations. To do proper analysis of experiences, the participants have to overcome subjective or private feelings, but as stated, this is an impossible act to fulfill. Qualitative research is often conducted by doing interviews. Interviewing people who are seriously ill or people who are dying involves ethical issues and therefore they are rarely conducted. In this section I outline the contours of teaching communication using autobiographies built on the assumption that data are not necessarily to be collected by interviewing, data is everywhere in our everyday life (Brinkmann, 2012). It is important to point out that an interpretation of an interview is not automatically equal to a phenomenological analysis: to do this kind of analysis requires focusing on a special ´moment´.

Contemporary theory of phenomenology represented by Patricia Benner in nursing research – together with Max van Manen in education offers ways to solve some of the problems outlined above. Benner and van Manen both do phenomenological interpretation by working with descriptions of lived experiences as texts. As stated by van Manen we cannot overcome our subjective or private feelings. Neither is it possible to "escape" our pre-understandings and assumptions – this material needs to be explicated and examined. Benner suggest paradigm cases, exemplars and thematic analysis as interpretive strategies (Benner, 2010). These strategies are all useful when analyzing the autobiographies. These texts represent the individual stories but can also function as paradigm cases and exemplars discussed in groups involving a variety of perspectives and focusing on the existential challenges as subject for thematic analysis, that is, the autobiographies are seen as examples of possible human experiences. The question is: How does illness interrupt human life as well as the question: How to live the everyday life including existential/ spirituals matters? I suggest that health practitioners read and discuss autobiographies in order to explicate first, what is the ordinary embedded in the extraordinary in these narratives and vice versa; second, what is contained within the bracket of assumptions, presumptions, common understandings and scientific explanations. In other words: What "knowledge" belongs to the professional, the personal and the private sphere? When I presented a list of autobiographies published since 2000 at my course many of the nurses were familiar with the autobiographies but the reading was seen as a personal or private activity. It is necessary to work with the capacity for reflexivity and here the autobiographies and arts come into play.

As we saw in the titles and in the themes of the three autobiographies the task is how to be aware of views, judgments and assumptions, when we first of all lack a proper language to talk about existential/spiritual matters. What to say and what to do being in No Man´s Land, being in The Waiting Room waiting for death, and finally how to deal with Taboos about being ill? What makes me wonder is the fact that related to narrative of illness or of dying is almost for certain a narrative about life. It is described how illness disrupts human life, and the authors are reflecting on the theme, how one ought to live. It seems as if meaning, being and time become clear in the light of death or illness. However, what we can do is pointed out by Deurzen and Adams, existential therapists: "While we can never feel what the client is feeling, what we can do is to take their experience into ourselves and engage and resonate with it" (Deurzen and Adams, 2011, p. 31). Before exemplifying how to take experience into ourselves and engage and resonate with it, let us have a closer look what is important in a pedagogical setting concerning communication.

Communication in the learning practice of the nursing profession

The statement concerning theory and techniques mentioned by the nurses above points to a key point showing that we are dealing with a complex task. No technique is capable of delivering what is asked for here: to understand the world of other people, their beliefs, their attitudes, their responses to illness, and the path each person is to take in order to overcome distressing experiences in life. Concerning the spiritual ´part´ of the perspective, the question about beliefs is even more problematic as it in general belongs to the personal and private sphere and language is missing.

Finally, how are various genres to be used as learning spaces for healthcare providers in practice? By examining examples it is possible for nurses to refine their individual capabilities in collaboration with one another in a way which reduces the sense of vulnerability, anxiety and helplessness related to spontaneous and unprepared conversations about life and death. A statement mentioned by a professional in the beginning of the article was: I need more theory to give my answers a safe basis. Probably, the solution is not more theory but an integration of theory with lived experience descriptions, one´s own together with descriptions of others. In difficult communication dilemmas are often at stake; there are no simple questions and no simple answers. Empowerment by discussing dilemmas (Jacobsen, 2008), establishing a ´knowledge-lab´ (Erstad and Hansen, 2013) or a ´practicum´ (Schön, 1987) or working with a problem based learning model are paths to follow. Establishing a lab where healthcare professionals by using autobiographies as well as other art products can work with not only the narratives of others, but also with their own narratives – self-reflection - in a non-therapeutic setting. Bringing together novices as well as experienced nurses opens up for the possibility to wonder and learn from this from different angles and from a variety of perspectives. Van Manen asks the question: Is it possible to bring others to wonder? He illustrates the answer with an anecdote[5]: One night when driving home by car in in the Canadian woods together with his two children, he stopped the car and looking into the dark sky he wondered about life, meaning and the universe. Asked, the children also wondered, but they were more concrete; they wondered about danger, wolves and being afraid of the dark. Children, adults, young and elderly people do wonder, but you never can tell their perspective. This is this kind of different perspectives I have in mind when working with autobiographies and arts in a lab, where professional, personal and private experiences are brought into play. I take for granted that our consciousness do not consists of three boxes labeled professional, personal and private, experience is a much more complex phenomenon.

The goal is to enable professionals to listen to narratives and to hear the unspoken, to be able to take several perspectives into consideration, and to enable them to be counselors for patients and relatives concerning existential matters related to overcoming the distressing experiences of being ill. That is: to motivate, inspire and guide behavior of patients and relatives in the present – being ill - and in the future living with a lifelong disease or living as a survivor. Furthermore, the goal is that participants should be able to engage in the contemporary existential-phenomenological debate, to identify and describe the important concepts and to apply an existential and phenomenological approach to their professional life.

If we are to take narratives and the perspective of patients and relatives seriously in the effort to make people co-constructors of health and wellbeing, the communication must be formed as a conversation, a dialogue, a meeting, a real talk – not as information transmission from an expert to a non-expert. If communication training is to become an important part of health care service, it will be expedient to make a connection to concrete contents and build a bridge between medicine and nursing, for example through common training including doctors and nurses. As stated by Nerheim, professor in philosophy, who is working with science and communication: "To communicate is to share the world of the other" (Nerheim, 1995, p. 274, my translation). That is, communication is no add-on activity, and health care professionals, patients and relatives are all to communicate. Further challenges to discuss are: how to engage patients and relatives, how to handle informed medical decisions and shared decision making – all including bio-psycho-social as well as existential/spiritual perspectives. These perspectives could perhaps be part of developing the field of narrative medicine in the 21st century within the frame of human science.

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Notes

1 The titels in Danish: *Dødens psykologi* in K.M. Dalsgaard og M.H. Jacobsen (red.)(2011) *Humanistisk palliation,* Hans Reitzels Forlag og *At skabe rum for kommunikation: Narrativ terapi og musikterapi som form og forum i familier med et kræftsygt barn* in A. Horsbøl og M.B. Sørensen (red.)(2010) *Sundhedskommunikation på sygehuset,* Aalborg Universitetsforlag

2 Congress of Qualitative Inquiry, U.S. 2012 and 2013; Engaging people in health promotion & well-being, Italy 2012 and The 32nd International Human Science Research Conference, Denmark 2013, The Art of Communication, Denmark 2014 and The 33rd International Human Science Research Conference, Canada 2014

3 Sundhedsstyrelsen. (2012). *Forløbsprogram for rehabilitering og palliation i forbindelse med kræft - del af samlet forløbsprogram for kræft.* København: Sundhedsstyrelsen

4 The titels in Danish: Ingenmandsland, Venteværelset og Tabuknuseren

5 The anecdote is described in total in Van Manen, 2014, p. 361