Conversation or non-versation? Physicians’ communication about existential, spiritual and religious needs with chronically ill patients - protocol for a qualitative study

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Published in:
European Journal for Person Centered Healthcare

DOI:
10.5750/ejpch.v7i2.1715

Publication date:
2019

Document version
Accepted manuscript

Citation for published version (APA):

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Background

When people face serious, chronic illness, they might describe their normal life as replaced by a “fundamental uncertainty of being in the world” and express a need for support from health professionals through empathic listening to them as unique human beings (1). Care-oriented aspects are important to improve patient health outcomes, giving them the feeling that they have been understood and have not been left abandoned (2, 3). One way of meeting these wishes is to focus on the patients’ existential needs (4, 5). In international studies, patients’ existential needs are defined as secular (without relations to spiritual and religious faith or practice) as well as spiritual and religious, and are experienced not only in palliative care, but also in patients with chronic diseases such as multiple sclerosis or chronic pain (6-8). If patients with chronic illnesses have existential needs related to health, and empathic communication with professionals improves health outcomes, it is relevant to explore if and how physicians address and communicate with patients about these issues and needs.

Barriers to existential communication

As shown in the literature, physicians often intend to address the patients’ individual situations and illness perspectives (9), or acknowledge that they should be aware of the patients’ spiritual beliefs especially in palliative care near death (10). However, research suggests that such care is not always provided. In a U.S. study, only every fourth patient with advanced cancer reported high support of their spiritual or religious needs (11). A Danish study, investigating how general practitioners (GPs) address and integrate the existential dimension in the encounter with the patient, found the existential dimension to be often integrated in unsystematic ways and that GPs generally avoided religious and spiritual aspects, although existential communication was emphasised as an important part of the encounter (12). Barriers for physicians’ systematic engagement in all aspects of existential communication include lack of time, self-awareness, professional education and training (10, 13, 14).

Spiritual care involves existential communication

Meeting the patient as a whole person (10, 15) suggests a focus on patient involvement and on the individual, social and cultural aspects influencing illness and health (16). An extended version of this interactional model of care perceives suffering not just as a physical, psychological or social matter but also as a spiritual one (10, 17). This implies that treatment and care must relate to and reflect all areas: physical, psychological, social and spiritual (17). “Spiritual” is defined as the various ways in which people transcend their individual border to make meaning in life either through religion or in relationships with family, art or music (17). This approach is defined by WHO and established for example in palliative care as “spiritual care” but is also recommended and evolving in other health areas (16, 18, 19). The tendency in health care to recognise spirituality and religion as part of human culture also reflects a general direction in the post-secular societies (20). Post-secular societies can be defined as a recognition of spirituality and religion in a former secular country, and this recognition enables a dialogue on how to combine the secular with spirituality and religion (21).

Focusing on existential themes and issues within spiritual care (what we call “existential communication”) may include both meaning-making in secular ways, as rooted in human
experience and nature without any transcendent reference (22), but also in spiritual or religious ways (23, 24). The term “existential” concerns fundamental human conditions such as freedom, loneliness, death, suffering and how one’s value structure and meaning in life operate in response to these conditions (25-27). Existential meaning-making can be entirely secular but may also integrate spiritual and religious themes (23). In the current study, “spiritual” is defined as an experience of relatedness and ‘orientation towards an immaterial, cosmic power’ (28) which is distinct from secular meaning-making and thereby more specific than broad definitions of spirituality (17, 18). Religious meaning-making draws on beliefs, practices and rituals related to any form of the transcendent and are derived from founded traditions developed over time within a community (22). These are very different, yet overlapping, ways to make meaning, and “existential communication” is defined as any kind of communication that addresses the existential, spiritual and religious needs and ways to make meaning in life.

In addition to the recommendations to integrate existential, spiritual and religious care in the interactional model, patients welcome a more “holistic” treatment including being asked about their spiritual belief if they become gravely ill (29, 30). These findings emerged primarily from studies conducted in the U.S., but even in a less religious society such as Denmark, patients expressed existential needs such as identity challenges, experiences of a fundamental disruption of their lives and an ontological uncertainty especially when they just received the diagnosis (1). In more secular countries, existential, spiritual and religious needs are considered to be private, and patients are often unfamiliar with expressing concerns in these directions (31, 32). This indicates the need for more support from health professionals in an empathic way (33) that will allow the patients to be open about, find ways to formulate, and discuss such issues with their health care provider.

**Theoretical underpinnings**

The present project is inspired by theories put forward by the psychoanalyst Balint who described a person-centred approach to the patient/client as relationship-centred. The relationship between the physician and the patient has many similarities to the relationship between a psychologist and a patient in psychotherapy (34-36). The relationship is accentuated as essential which was also evident in the original concept of patient-centredness (35). In the philosophy of Martin Buber, relationships are vital for being a human: In a meeting between an I and a Thou, the other becomes a subject as opposed to I and It where the other becomes an object, and such a meeting can only occur in a moment without purpose and means (37).

Seen from this philosophical perspective, when a physician’s caretaking is based on the bio-psycho-social-spiritual model, it is important to be open and try to facilitate a meeting between an I and a Thou. If the patient only becomes an object, or a diagnosis with a bunch of symptoms, meeting the person and thereby also knowing the patient’s function, health and possibilities are lost opportunities of positive change (38). To meet the patient as a Thou requires that the physician brackets his/her own professional assessments and, in the few moments in the consultation where the opportunity arises, meets the patient as an equal human being (38), without considering in the present moment what this meeting can be used for (39). The total presence is not possible all the time but without it in the communication, according to Buber, you will not meet the human (37). Following Buber, to experience oneself in a relationship with a Thou is the precondition of real life, of being an I (37). Following this idea, we hypothesise that meeting the patient not only as a patient with a diagnosis and certain symptoms but also in some moments...
with an intense, intersubjective contact as an equal human being, will affect the patient’s wellbeing, health and coping strategies in a positive way. In existential communication, the presence that enables a meeting between an I and a Thou acknowledges the patient on a fundamental, existential level, hereby alleviating existential concerns such as loneliness (38).

Framework for analysing existential communication

Communication is understood as interaction between two or more participants and as the active, dynamic way they co-create meaning (40-42) (see figure 1). The physician and the patient each enter the consultation with preconceptions based on prior experiences and knowledge, which might only be partly conscious and as such unstated (38). Engaging in the communication enables their perspectives to fusion and new shared understandings are made possible (43, 44). The model illustrates, how we understand existential communication as embedded in the consultation, and as such an interactional process that contains the possibility of a presence where the patient is met as a Thou, a subject more than an object, a human being more than a patient. Furthermore, in this consultation an opportunity is integrated for the physician to meet the patient as a subject thereby indirectly intervening at the existential level by meeting the patient as an equal human being.

Informed by existing research about healthcare professionals’ attitudes towards communication about psychosocial existential and spiritual patient needs (12, 42), we expect that some of the health care professionals will need training and supervision to feel comfortable asking patients about existential, spiritual and religious needs. Otherwise, they may rely primarily on their own private experiences when meeting the patients’ existential needs in the encounter which will make the approach randomized instead of systematic and professional (figure 1).

In the selected groups of patients, we expect to find existential, spiritual and religious needs due to the existential challenges most people experience when facing chronic disease (1, 45, 46). Patients might not be familiar expressing their thoughts in relation to these needs (31), and therefore we expect that factors, such as time spent in consultations and the practitioners’ openness to and professional knowledge about these needs, influence the degree to which the patients reveal their existential, spiritual and religious needs. This corresponds to the approach in the original patient-centred concept as suggested by Balint (35) in emphasising the physicians’ responsibility for responding also to the patients’ unexpressed needs in a therapeutic relationship.

Figure 1: Existential communication as an interactional process and potential subjective meeting


Aims and research questions

We aim to a) study the approach of physicians to existential, spiritual and religious needs in relation to patients with chronic illnesses and b) explore how patients experience existential, spiritual and religious needs in relation to their chronic disease and satisfaction with their overall treatment. Further, we want to compare two diseases to see if some of the needs found might be disease-specific or similar across diseases.

Receiving a diagnosis can be a way to find meaning and structure in an otherwise chaotic experience of symptoms and disabilities (47), but it takes time to readjust (4). We will study patients who recently got their diagnosis and compare their existential, spiritual and religious needs with those who have been living with their diagnosis for several years.

Research questions

1. How do physicians experience and address the existential, spiritual and religious needs of patients with chronic diseases?
2. What are the existential, spiritual and religious needs of patients with chronic diseases, and do the needs change in relation to the course of the disease or differ between diseases? How do patients with chronic diseases experience the communication with physicians about their needs?
3. What facilitators and challenges do both physicians and patients experience when communicating about these needs?

Methods

Study population

To answer the research questions, we have selected two groups of chronic diseases: multiple sclerosis and chronic pain and recruit patients diagnosed with and physicians treating patients with one of these two diseases.

- Multiple Sclerosis (MS) is a neurological disease among young adults associated with significant impact on the patient’s health and quality of life (45, 46, 48, 49). The suicidal risk in MS patients is twice as high than in the general population and especially for men, aged <30, and in the first years after receiving the diagnosis (46). Its prevalence is especially high in Denmark (50, 51).

- Chronic Pain (CP) defined as biomedically inexplicable, non-malignant pain lasting more than six months, which is associated with reduced daily functioning, inactivity, and depression (52, 53).

Although MS and CP are biomedically distinct diseases, they both include pain as a severe and chronic symptom. Further, due to the chronic nature both diseases require long-term treatment with cure and care-oriented aspects of the doctor-patient communication.
When studying private concerns, such as the existential, spiritual and religious needs and communication, the qualitative methods work well towards in-depth knowledge of the complexity in the subjective experiences. The present study employs semi-structured interviews and participant observations as data generation methods. Interpretive Phenomenological Analysis (IPA) is employed as methodology given that it is based on phenomenological-hermeneutic positions well suited to explore subjective meaning-making.

This qualitative study comprises two sub-studies: Part study 1 investigating the physicians’ perspective and part study 2 – investigating the patients’ perspective. Conducting two studies allows us to explore existential, spiritual and religious needs from different viewpoints, as a kind of triangulation. A purposeful sampling technique will be employed in order to recruit enough participants to conduct an accountable analysis. Our sample size is based on the ideographic approach of IPA recommending smaller sample sizes. The number of participants is estimated to achieve sufficient information power.

Part study 1: Participants in this part study will be physicians working with the two disease groups. The physicians are recruited through the senior consultant and through “snowballing” at the Department of Neurology and the Pain management Clinic at Odense University Hospital, Denmark. Participation is voluntary, and no compensation will be given.

At each of the wards semi-structured interviews with four physicians are planned, resulting in eight interviews with physicians. We schedule half an hour to 45 minutes for each semi-structured interview, and the interview will take place at the physician’s ward.

Part study 2: Participants are patients suffering from chronic pain or multiple sclerosis. The patients are recruited from the Department of Neurology and the Pain management Clinic at Odense University Hospital, Denmark through the physicians, the effect of “snowballing” and through announcements posted in each ward. At one of the collaborating wards, in the general evaluation scheme following end of treatment, the patients can give consent to receive further information regarding participation in the study, and the first author will contact everyone by telephone. Participation is voluntary, and no compensation will be given.

Interviews with 12 patients from each disease group are planned. We schedule half an hour to 45 minutes for each interview and the interview will take place on a location of the patient’s choosing either in a quiet room at the hospital setting or in their private homes.

Researcher reflexivity

To obtain transparency about the possible ways the researchers’ preunderstandings might influence the research process, we describe the authors’ background and former experiences related to the current research project. The author group consists of qualitative researchers, experts and researchers in clinical practice and in spiritual care. The first author conducts the interviews and, as a trained psychologist working in clinical practice prior to the PhD-project, awareness and self-reflection are important regarding the differences between a research-interview and a clinical interview. Further, when interviewing the physicians, the interviewer tries to bracket own experiences of being a therapist in the engagement of understanding the other practitioners’ experiences. This is done by asking open questions in a semi-structured way, creating a space where the interviewee feels safe to further elaborate on the posed questions, and by inviting co-authors to listen to the audiotaped interviews and read the transcripts. Any
suggestions will be discussed and implemented as required. International studies have investigated the existential, spiritual and religious needs of patients with chronic pain and multiple sclerosis (7, 58, 59). Consequently, this knowledge is a part of our pre-understanding together with a few studies on the approach of physicians showing that physicians in chronic pain treatment rarely meet these needs (60, 61). Due to the gap of knowledge in how physicians communicate about existential, spiritual and religious needs and how patients also in a Danish, secular context experience and communicate about these needs, in-depth description and analysis are needed. Approaching the interviews and the process of interpretation and analysis, our practice therefore is open and explorative as we want to understand the patient’s and physician’s experiences and needs.

Data generation

The semi-structured interviews are conducted based on an interview guide that contains open questions relating to the above three research questions (see appendices 1 and 2). The interview guides focus on the participant’s experiences of the existential, spiritual and religious needs in relation to disease, treatment and satisfaction with the communication between physician and patient. If new questions emerge from the data as the project proceed, these will be added to the original interview guide for the remaining interviews. All interviews are digitally tape-recorded, stored as MP3 files in a secure manner and transcribed verbatim prior to data analysis (62). The first author will conduct the interviews and validate the quality of the transcripts by comparing the recording with the transcripts (63).

Analysis

The analysis of data deriving from both part study 1 and 2 will follow the steps of Interpretive Phenomenological Analysis (IPA), including an idiographic approach, which means that one transcript will be analysed in its entirety before moving on to the next. First analytical step includes listening to the audio-recordings and re-reading the transcripts to be immersed in the data. Secondly, we will take initial notes during listening and reading and make comments on the material. Then, we will note emergent themes before searching for connections across them. Themes will be checked continuously against the transcriptions to maintain the empirical foundation and quotations from the interviewee are added to illustrate each theme. The coding process (developing themes and subthemes) is progressing through ongoing discussions with co-authors (KKR, EAH, NCH). We will provide a transparent and rich description of the context of our participants’ narratives allowing analytical transferability to more or less similar contexts (43).

Ethics approval

The study has been approved by the Danish Data Protection Agency (J.nr. 17/63393). The University of Southern Denmark (SDU) is the controller for processing of personal data in connection with the project, which has been included in SDU’s internal record of processing activities under file number 10.218, cf. GDPR Article 30.

Consent for Publication

There is always a risk for the patients to give socially desirable responses about their physicians because of anxiety that a critical answer would adversely affect their care (Zachariae,2003). This risk is perhaps bigger because of the inevitable lack of total anonymity in qualitative studies. We have tried to overcome this by delivering information about the study before the patients agree to participate, by giving them the opportunity to be interviewed at home instead of at the
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department and by recruiting after they have finished their treatment at the department when possible.

The patients and physicians will give written consent before participating in the study, and at any given time they have the possibility to withdraw said consent and are informed about this upon giving their consent. In the beginning of every interview the interviewer is clear about the anonymization-process: The patient’s statements will be pseudo-anonymized in relation to the Danish data agency protection and will by no means affect the possible actual treatment. This is also done to inspire confidence and encourage patients to talk freely. Further, the interviewer informs the patients that being interviewed about personal needs might affect the patient psychologically afterwards and encourages patients to see the physician or psychologist if rumination or any questions occur. The first author is aware of participant identities throughout the study to accommodate with patients or health care providers possibly withdrawing consent. The key to de-anonymizing the data is kept securely with the first author.

Availability of data and material

Data will not be made publicly available because it is not possible to make data anonymous as personal information are revealed. Data will be uploaded to a password-protected server at the University of Southern Denmark where logging is possible, and backups will be made. The corresponding author and the senior author have access to the data throughout the project-period. For data to be shared with other authors in the research group, we will use the research group’s common drive at the university’s secured server.

Discussion and Perspectives

Receiving a chronic diagnosis and managing to live with chronic pain can challenge existential wellbeing and the way the person used to make meaning in life. Little is known on how chronically ill patients experience existential needs in relation to treatment and on how physicians communicate with the patients about these needs.

With this study, we will extend the knowledge base on how physicians understand and approach chronically ill patients’ existential, spiritual and religious needs. We assume that the health professionals will understand the existential communication from a secular existential perspective primarily focusing on personal values, loneliness and meaning in life (23). Furthermore, this project will hopefully enhance the knowledge of patients’ existential, spiritual and religious needs in relation to chronic illnesses. This will improve the possibilities for treatment and, by outlining the challenges and opportunities of care, enhance the quality of treatment of chronic diseases. Studying two groups of patients allows us to compare the results and look for diagnosis-specific differences as well as similarities. Similarities across diseases could indicate shared needs for people living with a chronic disease. Further, the results of this study can enhance the continuous learning of health care professionals regarding existential communication with chronically ill patients.

Existential communication is in line with the tendencies in a post-secular country of integrating care of the whole person (64) – not only the biopsychosocial needs but also existential, spiritual
and religious needs. Based on philosophical and psychotherapeutic knowledge and perspectives, what is essential in patient-centred care is to meet the patient as a person. Taking up the challenge of balancing between all four dimensions of the patient (bio-psycho-social-spiritual) may help health care professionals to not forget the human in the patient.

**List of abbreviations**

Not applicable

**Declarations**

The authors declare that they have no competing interests.

**Funding**

The Strategic Research Counselling in Region Southern Denmark; The Trigon Fond

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