




'Maybe we are losing sight of the human dimension' – physicians' approaches to existential, spiritual, and religious needs among patients with chronic pain or multiple sclerosis. A qualitative interview-study

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ABSTRACT

Objective: Research suggests that existential, spiritual, and religious issues are important for patient's psychological adjustment when living with chronic pain and multiple sclerosis. However, there is a paucity of studies investigating how physicians experience and approach these patients' needs.

Design: Physicians' experiences with and approaches to existential, spiritual, and religious needs when treating chronic pain or multiple sclerosis were studied in eight semi-structured interviews and analysed using interpretative phenomenological analysis (IPA).

Results: Physicians found that only few patients had spiritual and religious needs; however, they experienced that every patient were struggling with existential challenges related to the illness and rooted in a changed identity and approaching death. How the physicians approached these needs appeared to be influenced by six conditions: Their medical culture, training, role, experiences of time pressure, their personal interests, and interpersonal approach.

Conclusion: Physicians' training seems better suited to meet biomedical objectives and their patients' concrete needs than patients' wish for a relational meeting focused on their subjective lifeworld. This challenge is discussed in relation to modern patient-centeredness, doctor-patient relationship, culturally constructed experiences of privacy, and future clinical practice and research needs.

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Introduction

Suffering, illness, and confrontation with death can trigger an existential crisis that evokes a diversity of different existential needs (Cullberg, 1993; Frankl, 1982; Larsen, Hall,

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Jacobsen, & Birkelund, 2017). Existential needs are here understood in a pragmatic way including needs related to common human conditions such as death, hope, and meaning (Frankl, 1982; Yalom, 1980). For some people, relating to these existential conditions implies a religious or spiritual worldview or belief. Especially in times of distress and illness an increase has been shown in the use of religious and spiritual coping strategies such as praying and hoping (Cummings & Pargament, 2010; Kaye & Raghavan, 2002; Keefe & Dolan, 1986), although the relationship between religion and health is complex as evidenced in the literature around religious struggles (Exline, 2013; Exline, Krause, & Broer, 2016). The relationship between spirituality, religion, and health has further been a subject in physician–patient communication, however, the majority of studies regard end of life care or general practice (Best, Butow, & Olver, 2016). We aim to study how physicians experience and address existential, spiritual, and religious issues and needs in the encounter with patients suffering from non-malignant severe illnesses.

Religion has been defined as a specific focus on beliefs, experiences, and practices that are perceived to have a sacred character, related to any form of transcendence, and developed over time within a community (Koenig, King, & Carson, 2012; Pargament, Oman, Pomerleau, & Mahoney, 2017). Sacred is here used as a broad concept incorporating also non-traditional, non-theistic expressions such as the environment or family (Pargament et al., 2017). Spirituality is the orientation that transcends the self either as a quest for the supernatural, including an immaterial, cosmic power (Ahmadi & Ahmadi, 2017; Schnell, 2012) or as this-worldly, expressed, for example, as a belonging to nature (Schnell, 2017).

The relationship between biomedical explanations of diseases and holistic or religious explanations is historically complex. Modern Western medicine is rooted both in Greek inspired holistic models of illnesses and in religious explanations of diseases (Porter, 2003). However, knowledge about diseases from post-mortem examination lies at the root of modern medicine's scientific power with its strong focus on the individual body, presenting medical knowledge as a rational, objective field separated from holistic models and religious explanations (Elsass & Lauritsen, 2006; Foucault, 1972/2000; Porter, 2003). In recent years, scientific studies have rediscovered the relationship between religion, spirituality, and health, and they have shown that religious and spiritual activities can serve as a beneficial way of coping with pain and other somatic symptoms (Koenig et al., 2012, p. 531). Thus, research on the relationship between physical and mental health, and religion attests to a renewed recognition of the importance of existential, spiritual, and religious issues in medicine (Abu-Raiya, Pargament, & Krause, 2016; Büssing & Koenig, 2010; Koenig et al., 2012; Puchalski, Blatt, Kogan, & Butler, 2014).

Chronic illnesses such as multiple sclerosis and chronic pain are characterised as chronic, non-malignant illnesses with unpredictable illness-trajectories. Patients with multiple sclerosis have shown an increase in suicidal ideation compared to the general population (Pompili et al., 2012) and an increased risk of depression (Anthony, 2011); a tendency that corresponds to chronic pain populations (Stenager, Stenager, & Jensen, 1994; Tang & Crane, 2006). Although the two illnesses are biomedically distinct, they both include pain as a severe symptom and require long-term treatment with a focus also on the psychological (depression) and existential (suicidal ideation) illness-related consequences.

Spiritual care – a type of healthcare encompassing attention to patients’ existential, spiritual, and religious needs – is already included in the World Health Organization’s (WHO) recommendations for terminal and palliative patients. However, there are no guidelines for delivering spiritual care to patients suffering from chronic diseases, although they also experience existential, spiritual, and religious needs as evidenced in specific studies (Büssing et al., 2009; Dezutter et al., 2016) and in Koenig and colleagues’ comprehensive review of different illnesses’ inter-relationship to existential, spiritual, and religious themes (Koenig et al., 2012).

In relation to patients with chronic pain or multiple sclerosis, overall, research show a positive association between existential, spiritual, and religious resources and psychosocial wellbeing. A recent review of 20 studies found an association between spirituality and religiosity, and psychological function in patients with chronic pain, suggesting that viewing one-self as spiritual may be a positive resource for psychological adjustment (Ferreira-Valente et al., 2019). However, the studies evidence methodological homogeneity and with cross-sectional designs, the review cannot draw any causal interferences (Ferreira-Valente et al., 2019). Many patients with multiple sclerosis seem to reappraise their illness in a positive way (Pakenham, 2008), which has been associated with faith (Büssing et al., 2013) and with a reduction in symptom-severity of depression and in pain interference (Nsamenang, Hirsch, Topciu, Goodman, & Duberstein, 2016). Both existential and religious wellbeing are associated with better psychosocial adjustment in patients with MS (McNulty, Livneh, & Wilson, 2004). Moreover, there seem to be an association between illness-related communication in the encounter with the physician when receiving the MS diagnosis and the adequacy of the patients’ coping-styles; meaning that the more satisfied the patients were the more adequate coping-styles were employed (Lode et al., 2007).

Despite these research findings, a systematic literature search gave no results concerning physicians’ approach to the existential, spiritual, and religious needs in the treatment of multiple sclerosis (MS) (conducted in the databases PsycInfo, Embase, Medline, and Scopus in June 2019). Some studies, nevertheless, reported on MS patients’ frustration with the brief physician–patient contact (Schwarz, Knorr, Geiger, & Flachenecker, 2008), indicating unmet psychological and existential needs in physician–patient communication (Shinto et al., 2005; Yukawa et al., 2018).

In a recent review on physicians’ approaches to existential, spiritual, and religious patient needs in the management of chronic pain only four studies were found (Andersen, Assing Hvidt, Hvidt, & Roessler, 2019). The results of the review suggest that physicians rarely meet the existential, spiritual, and religious needs of their patients with chronic pain. As a result, patients are often dissatisfied with physicians’ attention to their existential needs, leading to greater depression and higher levels of experienced pain (Dezutter et al., 2016).

When patients experience existential, spiritual, and religious needs related to their illness and the derived consequences, it might be important for their illness-experiences and health that the physicians not only address the biomedical perspectives but also the psychosocial-existential aspects (Dezutter et al., 2016). Asking a patient about illness-related experiences and needs might strengthen the physician–patient relationship and thereby strengthening the context also for treatment-related decisions (Gulbrandsen et al., 2016). Further, addressing the existential, spiritual, and religious illness-related

experiences can function as a guide for the physician to decide when to refer a patient to e.g. a psychologist or a chaplain (Best et al., 2016). Thus, the associations between the communication in the physician–patient encounter and the existential, spiritual, and religious needs of patients with chronic pain or multiple sclerosis make the current study relevant. Due to the paucity of studies of these specific patient groups, the following two research questions were posed: 1. How do physicians experience their patients’ existential, spiritual, and religious needs in relation to chronic pain and multiple sclerosis? 2. How do physicians approach existential, spiritual, and religious needs in the encounter with the patient?

Method

Methodology

When studying physicians’ experiences with addressing patients’ needs during the clinical encounter, qualitative methods such as semi-structured interviews are well suited to generate in-depth knowledge of the physicians’ subjective meaning-making. Interpretative phenomenological analysis (IPA) comprises an inductive, phenomenological-hermeneutic stance and insists on analysing each individual case before looking for themes across cases. Employing IPA therefore ensures that each physician’s voice is heard in the findings and leads to a nuanced and rich description of the phenomenon.

Participants, sampling, and data collection

Participants in this article comprised physicians specialised either in treating patients with multiple sclerosis or with chronic pain. They were recruited through senior consultants from hospitals in the Region of Southern Denmark. A purposeful sampling technique was employed. Based on the initiated analytical process of the first three interviews, five more interviews were conducted. To ensure equality of the numbers of physicians from each ward, the last interview was included. In the pragmatic model of *Information Power*, sample size depends on how much information power the sample holds; the larger information power the lower number of participants, and vice versa (Malterud, Siersma, & Guassora, 2016). We followed the model and discussed the sample size as recommended in relation to aim, specificity, theory, dialogue, and analysis (Malterud et al., 2016). Further, we discussed how much information was obtained from the sample, and the size was estimated to have achieved sufficient, relevant information power. Eight physicians between 34 and 76 of age participated, five of them were females and three males. The physicians were treating either patients with MS or with chronic pain at specialised wards; the four physicians treating multiple sclerosis were neurologists, and the other four had anaesthesia or general practice as their formal background before specialising in the treatment of chronic pain. The duration of their encounters with the patients were normally between 45 and 60 min. Due to anonymity issues, the physicians’ specialities will not appear in the result section or in the quotes. The sample size matches the ideographic approach of IPA (Smith, Flowers, & Larkin, 2009).

The first author conducted the semi-structured interviews with each participant at the physician’s ward. The interviews were guided by an interview guide containing open questions around the physicians’ understanding of existential, spiritual, and religious needs,

their experiences of and approach towards these needs in the encounter with their patients, and how important they experienced these needs were for their patients. The physicians were also asked if they thought their own stand in life interfered with their approaches towards these needs, if they felt prepared and equipped to address these needs, and if they experienced any possibilities or barriers regarding these themes in the encounter (the interview guide can be seen in Andersen, Assing Hvidt, Hvidt, Illés, et al., 2019). The interviews lasted from 20 to 60 min. The physicians gave written, informed consent before participating, and the interviews were digitally recorded, pseudo anonymised, transcribed verbatim, and stored at a password-protected server at the author's university together with the interviewer's fieldnotes from visits at the wards (Andersen, Assing Hvidt, Hvidt, Illés, et al., 2019). The physicians received no monetary compensation. The study was assessed for review by the regional ethical scientific committee and found exempted from the obligation to notify.

Researcher reflexivity

The first author has a background as a clinical psychologist. A therapy session and a research interview often involve conversation about confidential material, which requires a professional attitude of empathy and trustworthiness for the patient or interviewee to disclose their life stories (Fog, 1999; Kvale & Brinkmann, 2014). The first author was aware also of the differences between research and therapy regarding purpose, roles, and focus (Hall, 1996/2003), and tried to bracket own professional experiences to understand the physicians' views of their encounters (Knox & Burkard, 2009). Furthermore, co-authors listened to the audio files or read transcripts to check the quality of the interviews and to participate in the analysis. The three co-authors are all experienced researchers in the field of existential communication in medicine. Existential communication covers how health professionals communicate with patients about the diverse ways to make meaning in life, whether secular, spiritual, or religious (Andersen, Assing Hvidt, Hvidt, Illés, et al., 2019; Andersen, Assing Hvidt, Hvidt, & Roessler, 2019; Assing Hvidt, Hansen, et al., 2017; Roessler & Lindemann, 2014). Their prior understandings regarding the use of IPA and the selected themes have informed and enhanced this study and been a subject of discussion between all authors in the research process. In this article, we used the SRQR reporting guidelines (Standards for Reporting Qualitative Research) (O'Brien, Harris, Beckman, Reed, & Cook, 2014).

Analysis

Our analysis followed the main steps of IPA. At first, the researchers (AHA, KKR) listened to audio files and read and re-read the transcripts while writing comments and preliminary interpretations to familiarise themselves with the data material. Returning to each transcript, the researcher (AHA) looked at how each individual physician made sense of their experiences regarding their patients' existential, spiritual, and religious needs. Based on the initial notes, every sentence containing elements about how the physicians experienced and attended to these needs were gathered in one document, yet still disclosing each physician's separate perspective and speciality. The identified themes and patterns were listed and explored in order to search for connections between themes (AHA, KKR). For each

theme, a quotation was chosen to exemplify how the physicians experienced their patients' needs and addressed these needs (AHA). Afterwards, the researchers (AHA, EAH, NCH, KKR) looked for themes and patterns across cases while checking against transcripts continually (AHA) to ensure the empirical foundation and to avoid memory bias. As also recommended in IPA, the patterns found in the case analysis will be discussed in light of relevant literature in the Discussion section. Our analysis resulted in nine themes, which will be presented under the headings of the two research questions.

Results

How do physicians experience their patients' existential, spiritual, and religious needs in relation to chronic pain and multiple sclerosis? (Research question 1)

Despite illness-specific differences between the two included diagnoses, we did not find illness-related differences between the physicians' experiences of their patients' existential, spiritual, and religious needs.

Patients' specific spiritual and religious needs

In general, the physicians experienced that their patients expressed no wish for addressing spiritual or religious needs in the clinical encounter: 'It is seldom that they [the patients]¹ themselves raise a specific wish to talk about something spiritual'. Even so, some of the physicians still described patients' needs for spirituality as a subcategory to a patient's belief or religiosity, or as a spiritual need for finding inner calm as a way to relieve disease-related stress.

Religious needs were experienced mostly in those situations where professionals were asked to respect patients' religious worldview in connection with treatment, e.g. Jehovah's Witnesses who did not want to receive blood for religious reasons. One physician still experienced that a Christian patient expressed a need for combining treatment with pastoral care: 'I had a patient, who used the local priest. So, we talked about how I could contribute in relation to what the local priest did for her'. In this exceptional case, the patient expressed a religious need for pastoral care but also a need for integrating this aspect in the encounter with the physician. The physician reacted positively with an openness towards discussing religious illness-related perspectives with the patient: 'I thought it was fantastic ... [the patient] was really happy about the offer'.

Whereas only a few cases showed physicians' experiences with patients' spiritual and religious needs, experiences with patients' existential needs were much more common.

Struggling with the existential challenge of identity

According to the physicians, the question of identity constituted an existential challenge in their patients' life. They described identity as characteristics that differentiate one person from another. The identity challenge was perceived to be closely related to receiving and trying to manage a chronic diagnosis. Experiencing symptoms of the disease influenced not only the body but the patient as a whole person, as one of the physicians explained:

They [the patients] are in an existential crisis, many of them. Their whole identity, their before-and-after-life [life before and after the diagnosis], and there are some existential issues, [they ask]: 'who am I as a person, when I'm not the same person I used to be years

ago?' ... It's not always formulated as the most important thing when they come here ... but when you probe deeper, it is their whole identity that is at risk.

As seen in the above excerpt, reflections regarding identity as a person with a chronic disease were highlighted as important by the physician. However, the physician experienced that the patients would present more tangible aspects of their life, such as pain or economic challenges, before raising identity issues. Then, after probing into what was important, the underlying, subconscious problems were revealed to be the existential challenge to their identity. Due to this perceived challenge, from the physicians' point of view, the patients needed to reconcile themselves with a life that involved living with a chronic disease:

Many [patients] experience a huge feeling of unjustness: 'What have I done since I'm affected by this'. Our ultimate goal in treatment is that they make peace with themselves, reconcile ... with their condition (or situation), with their life ... But it is not something that happens overnight, it's a process, it's a part of life. And the sorrow related to 'being another' ...

From the physician's perspective, reconciling with the fundamental conditions in life is an essential part of living with a chronic disease and this may comprise feelings of injustice and sorrow because of the consequences of an altered life. By emphasising reconciliation as a process, the physician also indicate that existential issues can be evident at many time points in a patient's life, as also highlighted in the following quote:

I think that existential issues are always coming with crises and that the first crisis is at the time of the diagnosis ... if they have a severe relapse or something unexpected or the first treatment does not work ... and you have to change [treatment], then, of course, it is again a kind of crisis.

Considering the existential challenge of death

Death was mentioned by the physicians as a possible existential challenge for the patients since living with a disease subconsciously or consciously can be a reminder of the vulnerability in life and the fact that one day, this life will end. Some of the physicians explained:

Death is always present at some level when you have a disease, and then it is just subconsciously; you can say that death is there as a fear of things to turn out worse ...

If you are older ... and you have a chronic disease, you are anyway a little bit more existential ... because you are going toward the end of your life and ... the existential problems will come to the surface.

Physicians described their patients' having a fear of dying that would intensify with age as death drew nearer. Another way to be challenged by death, was to experience a breakdown in meaningfulness related to the fear of living with a permanent illness, which can lead to suicidal thoughts: 'It can turn out so bad that they almost have suicidal thoughts. There are many who can't see the point of anything when it hurts so much'.

The physicians believed that the identity challenges caused by the chronic disease were fundamental for the patients' way of living with chronicity. Furthermore, they assumed that death as a universal life condition could be more present when challenged by a chronic illness. Identity and death were the two primary existential needs the physicians

experienced their patients to have, although these needs were not mentioned right away in the encounter but at a later stage and sometimes rather implicitly in the communication.

How do physicians approach the existential, spiritual, and religious needs in the encounter with their patients? (Research question 2)

As seen above, a few physicians had experiences with ways to address existential issues related to the patient's current life situation; however, most found it challenging to deal with their patients' existential, spiritual, and religious needs. Analysing the data material, we found no group-related differences according to the physicians' specialities. Instead, the physicians' different approaches towards meeting these needs were influenced by four different themes with subthemes: *The biomedical approach* with *Medical training* and *The physicians' role* as sub-themes, *Experiences of time pressure*, their *Personal experiences and interests*, and an *Interpersonal approach*.

The biomedical approach

The physicians hesitated to deal with the existential, spiritual, and religious issues and needs, partly because they felt that the character of these issues was too private to address directly. The sense of privacy regarding these issues was thus pivotal for the physicians' approach. They anticipated that patients would find it strange if they were asked about their existential, spiritual, and religious needs:

If I start to discuss these things [existential issues], maybe the patient would be surprised ... they may be embarrassed, and they might feel that it is awkward because this is really something very personal ... definitely, you cannot ask in a direct way. It's also a kind of attitude of a nation and a culture, I think.

The physicians' feeling of privacy regarding existential, spiritual, and religious needs was also explained as being influenced by the research culture:

I think most of the patients would think of it as a strange question if I asked them, including the ones who think of themselves as believers ... [it] is intimate, almost like race or minority association ... It's very difficult for us to get permission to register things like that [race or religion] in studies ... so it's something quite holy.

The physicians' expressions of these needs as too embarrassing, personal, and holy to ask about might be shaped not only by the physicians' personal feelings but also by experiences from a general biomedical approach as in medical research in the above case. One of the physicians stressed that the biomedical approach in the healthcare system had changed over the last thirty years, leading to a focus on service more than trust:

Service is not about trust ... Maybe we are losing the human dimension of this whole thing, with the service part coming in ... I remember when starting my career, I was sitting ... even on the bed ... I just sat there and it's immediately a different connection and a different relationship than when standing ... So much has changed, and this all runs against the human dimension because I think all the existential issues are somehow the human dimension and not the service dimension.

A biomedical approach, where existential, spiritual, and religious needs are considered too private to ask about and where focus is on service rather than on trustful relationships

can challenge the physician's possibility for taking care of the existential conditions and issues.

Medical training. For the physicians, a further challenge in listening to the patients' existential suffering was their medical training that somewhat stood in the way of their existential care:

As physicians, we are educated to fix and to have happy patients, but that's not always reality. So sometimes, I just listen to what is hard and difficult ... it can be relieving for the patient just to be acknowledged in that [the experience] is shit. So, when you can't do anything else ...

When you are 100% from a natural science world ... , you have to redefine your approaches ... We are from a world where everything is measurable ...

In these physicians' views, being trained in the biomedical approach supports a treatment style where the physician obtains objective measures and 'fixes' the patient's problems. Confronted with problems that cannot be measured objectively and with no direct solutions at hand, this biomedical approach falls short, and the physicians are challenged to redefine their approaches.

Even though addressing existential issues in general was challenged by the physicians' educational background, it was clear that the spiritual and religious issues were the most difficult ones to take care of. Some of the physicians were reluctant to deal with these needs due to their medical, scientific background: "Don't poke a sleeping bear'. That's what I think religion is. Rather, we must adhere to our natural science'. Others asked for training to become more confident in addressing these needs:

It isn't second nature to ask about religion ... maybe we are reluctant to deal with it ... it is not very natural and maybe we also lack some tools to know how best to address it ... all healthcare personnel could benefit from training in these things.

The foundation for why some of the physicians felt able to handle existential needs was not their medical schooling but a personal interest in further training. Still, their approach also mirrored a concrete, objective manner matching their biomedical background, as in the following example:

[When] people cry, or I can see there is a huge, huge concern, then I ask them what this concern is about. Is it ... something totally indefinite or is it something concrete ... ? Then, we can either have a concrete approach, maybe talk about risks, percentage risks regarding this ... and try to be concrete.

In this example, the physician moved away from a medical focus on the body and attended to a potentially subconscious need when asking about the patient's concerns. Although the physician thereby recognised the need for a conversation about existential issues and fears, the physician preferred to reply to the patient's subjective concerns by relying on objective percentages and risks, indicating a medical focus on objective and concrete solutions.

The physicians' role. As we have seen above, most of the physicians would not attend to the existential, spiritual, and religious needs unless patients themselves expressed a need

for sharing their concerns. Some patients were described as aware of their own needs and capable of communicating them clearly in the encounter, for example the need for conversations with a priest. In one case in our data material, the physician focused on the patient's request for and satisfaction with the combination of spiritual and medical care; but as the interviewer asked further, if s/he used collaborative work with priests, s/he replied: 'No, we do not ... but if patients themselves bring it into play ... I respect, if they have sessions elsewhere'. This example illustrates that the physicians' role in relation to spiritual and religious needs can be characterised as 'passive respectfulness': physicians did not address these needs actively but respected if patients had needs, they tried to fulfil elsewhere.

The physicians actively addressed issues they considered important to explain and discuss with the patient, focusing on a biomedical perspective: 'My job is to try to give the patient an understanding of how we see this from a medical perspective'. Another one said:

It is like a school ... If I have something, I think is important, and I want to be sure that they [the patients] have understood it, then I can ask them to repeat it, for example.

When positioning themselves as medical experts in relation to the patients, the physicians' role became dominant in deciding what to talk about. The physicians in the present study practiced in a healthcare system with focus on patient-centeredness including shared decision-making (Department of Health and Prevention, 2015). This calls for an active, confident patient capable of addressing his or her own needs and taking responsibility for his or her own treatment trajectory (Mead & Bower, 2002; Vang et al., 2019). An example of the focus on shared decision-making can be seen in the following quote:

There are patients who would maybe rather like to try other kinds of stuff than our treatment which they are also allowed to. As long as they do it on a well-informed basis ... For example, one patient who would rather change his lifestyle ... and I thought my mission [offering treatment] could be accomplished concurrently - it could not ... And I'm not a salesman, I sleep well at night although he rejected my treatment as long as he understood the message about it.

In the above excerpt, the used wording indicates an implicit asymmetry, where the doctor as an expert tries to accomplish a mission: in this case convincing the patient to accept the treatment. Shared decision-making is here performed as the physician's permission to let the patient decide for himself how to deal with his illness after having assessed the patient's understanding of the medical message. The physician's use of the phrase: 'I sleep well at night' indicates that the patient's decline of treatment is not expected to impact the physician in an emotionally sleep-disturbing way. The physician thereby seemed to change his/her attitude from using the medical expertise as a mission for treatment to withdraw from the communication as the patient decided something different from the biomedical treatment plan. Thus, the physician will lack opportunities to address patients' existential concerns when withdrawing from the relationship. The physician's withdrawal from communication can be seen as being rooted in the physician's role in patient-centeredness with shared decision-making where addressing these needs is the patient's responsibility. The physicians' approaches towards these needs were founded in the biomedical approach, the physicians' training and role in the encounter, and interacted with patients' contributions to the communication.

Time pressure

In the Danish healthcare system, time pressure also played a role in the physicians' approach towards existential, spiritual, and religious needs. Some of the physicians experienced that the demands to what should be achieved in the encounter, such as practical issues, could take all the time in the encounter and effectively, precluded raising more abstract issues such as existential concerns: 'We spend ample time already trying to manage all the other things we have to do ... so if we are supposed to address these things also ...'. In this quote, the thought of communicating about existential concerns in the encounter is expressed as a demand or an extra burden because it is experienced as an addition to an encounter already characterised as being time pressured.

Personal experiences and interests

A further condition influencing the medical doctors' approach towards existential, spiritual, and religious needs was their personal experiences and interest in these issues. Several explained their reluctance to address spirituality and religion arguing that they were not religious themselves. Moreover, they referred to their personal experiences in their private life as the reasons for focusing on existential issues in a particular way:

I'm grown as a person and have been through enough of my own self-development and crises to be able to give something and to understand what they are going through [in their existential crises ...] But when you are young, you don't have so many tools to give anybody something, I felt powerless in the beginning.

Here, the physician's own experience based on personal life struggles became the 'tool' s/he used in the encounter in work life, and the way s/he reduced the feeling of powerlessness s/he felt earlier. Attending to the existential issues was not only a question of the capacity to transfer private experiences to professional tools, but also a question of an individual choice:

Some of the patients are better at accepting the limitations than others ... so, for me, it is important that we talk about these issues ... There is not so much consensus about these things [among colleagues], we don't talk that much about it either. It's just, either you have a flair for it or not. How much interest you have for the person, as a physician, is very individual, it's totally different how reluctant you are to deal with issues.

As argued by the physician above, to focus on the existential life situation of a patient with a chronic disease depends on the physician's own personal interest, judgment of the importance of the issue, and personal flair for this kind of communication more than on the very subject being discussed by physicians when deliberating on issues of treatment. This point assumes that whether and how a physician addresses patients' subjective needs depends on a combination of private experiences and personal choice when there is no consensus or specific training in addressing these issues.

As a result of specialised existential reading and training, one physician for example identified existential themes to be dealt with, including powerlessness, meaninglessness, and thoughts about death and the body's decay. This led to the view of the physician as the one who is responsible for inviting the patients to talk about the existential issues. Specialised reading and training seem to result in a proactive attitude towards existential needs.

The physicians' approach towards existential, spiritual, and religious needs was influenced not only by the biomedical approach, their training, own role, time pressure, and by their private experiences, but also by an interpersonal approach in the encounter.

Interpersonal approach

As evidenced above, physicians would listen to patients who brought up existential challenges themselves, but several physicians were in doubt as how to respond. However, some pointed out that being seen as 'a whole person' would benefit the patient, and therefore they actively used the relationship as an important part of the treatment. In the following quote, the physician addressed powerlessness in the encounter with the patient without suggesting solutions but instead listened with empathy:

To feel and dare to be with; or to be with someone, who dares enter the room where powerlessness is, together with them [the patients], this can actually be quite healing for the pain in relation to suffering a loss the way they do.

The physician's experience above refers to the understanding that trying to solve the powerlessness inherent in a chronic disease will be like trying to fix a fundamentally unfixable challenge: There is something in a chronic disease that neither the patient nor the physician can control. To be with the patient in moments with no feeling of control and endure powerlessness in chronicity therefore became an alternative to concrete solutions, which the physician experienced as healing for patients. Thus, the encounter became a room not only for medical treatment but also for relieving the existential suffering stemming from the consequences of having a chronic disease.

To ask the patients about their existential needs was furthermore explained as timesaving because they got straight to the point instead of circling around issues considered to be less important. Another advantage was a heightened understanding of the patient:

The presence is different from when we are just interviewing. You actually get insight into the person in front of you ... I can understand the patient better, why the patient has the kind of experiences he or she has.

Engaging in the patient in relation to the existential, spiritual, and religious needs required the physician's involvement at a personal level. On the positive side, it gave another presence and meaningfulness to the job. On the more demanding side, when delivering 'bad news' or in cases where patients did not accept the proposed treatment plan, it was also explained as difficult conversations to have and as taking away the patient's hope. Still, listening to the patient's feelings and worries helped the physician to not getting worn out:

There are patients who tire us out ... but when I remember listening and just to be with them, then, then something happens ... sometimes it is helpful ... just to listen.

The physicians described that engaging in an interpersonal approach, focusing on importance and meaning more than solutions, and listening with empathy to existential challenges could be personally demanding but also a healing process for the patient and thereby a meaningful way to help the patient.

To sum up: Some of the physicians included in this study addressed existential issues, whereas all of them hesitated to ask patients about spiritual and religious needs although some expressed an openness if patients themselves presented needs in this direction. In

order to understand the variety in experiences and approaches among the physicians, we suggest that the following conditions might be productive: The physicians' biomedical approach and training in a biomedical view on the body and a practice embedded in a culture of privacy regarding these needs replaced taking care of these needs with a focus on service, own role in shared decision-making, and a feeling of time pressure. Furthermore, physicians' private experiences and special interests together with a focus on an interpersonal approach influenced the way physicians addressed these needs. Although physicians recognised patients' needs, their approach towards existential, spiritual, and religious needs appeared to be highly personal due to the individual interplay between the six dimensions influencing their discourse and approaches.

Discussion

This present article studied how physicians experienced and addressed existential, spiritual, and religious needs in their encounters with patients suffering from chronic pain or multiple sclerosis. In general, the physicians' experiences did not differ according to their speciality; both groups of physicians experienced patients to have a need for addressing the existential challenge of identity and death, and more seldomly to express spiritual and religious needs. This could indicate that across specific non-malignant illnesses, an unpredictable, severe chronic course of disease might result in similar illness-related needs in relation to existential, spiritual and religious resources and challenges. The physicians differed in terms of how they chose to cope with these needs. However, none of them actively addressed spiritual and religious needs as they found them too private to address without further training. Their different approaches towards these needs did not apply to the illness they were treating but were influenced by a combination of their biomedical approach and training and by their own private experiences and interests regarding existential issues. Physicians' approaches to existential, spiritual, and religious needs were also influenced by an interpersonal approach in the encounter, focusing on making meaning more than devising solutions. Overall, knowledge about patients' existential, spiritual, and religious needs and how to take care of these needs as a physician was not part of their educational background or training, wherefore these needs were only addressed if the physician had a personal interest in them. Still, there seem to be a conflict between experiencing patients' needs and not possessing knowledge about how to take care of them. Our analysis suggests that physicians in general are trained to meet their patients' concrete, biomedical needs but challenged when patients call for an interpersonal approach and a focus on their subjective needs. This challenge may be rooted in the historic separation of medicine and religion because this separation stresses a one-dimensional biomedical focus on the physical body. In the following discussion, the challenge will be discussed in relation to patient-centeredness with shared decision-making, the encounter as an opportunity for a subjective meeting, and the cultural experience of privacy.

Patient-centeredness

Despite the recent rediscovery of the relationship between spiritual, religion, and health, the stories of the physicians of this study reveal a tendency in modern medicine towards marginalising existential, spiritual, and religious needs. Unexpectedly, a possible

reason for this may be found in the contemporary focus on *patient-centeredness*, which includes dimensions like shared decision-making, a symmetrical relationship, and a focus on the patient's role obligations (Mead & Bower, 2002). In this understanding of patient-centredness, the patient is in charge of her or his own treatment trajectory and responsible for expressing expectations and needs (Vang et al., 2019). This kind of physician–patient relationship is found to operate on a content level with conscious reflections that may disregard more sub-conscious needs, and it hands over the responsibility for addressing these needs to the patient (Vang et al., 2019). In our data material, all physicians showed a contemporary focus on patient-centeredness regarding their patients' spiritual and religious needs as they expected their patients to address these needs themselves. The physicians' way to manage their medical responsibility and expertise in a system with focus on shared decision-making was to teach patients about the biomedical perspective and let them decide for themselves if they accepted the biomedical treatment plan or would rather search for other solutions on their own hand. In the case from our analysis, the physician handed over responsibility for treatment decisions to the patient and seemed to withdraw from responsibility for treatment after having delivered the medical message, thus avoiding asking the patient how s/he managed to live with the existential consequences of the chronic disease. In a culture of patient-centeredness including shared decision-making, the focus on the biomedical perspective hence became a barrier to addressing existential, spiritual, and religious issues.

In a healthcare system that includes shared decision-making, emphasis on patient-centeredness may harbour a possible conflict for the physicians, as suggested in our study. On the one hand, the physicians possessed objective, concrete perspectives derived from their medical education and, on the other, they met a different reality in the encounter with patients exposing an interaction of objective symptoms and subjective experiences including existential, spiritual, and religious needs and positions (Thompson, 2007; Vang et al., 2019). When recognising patients-needs that one might not feel comfortable taking care of, a possibility is to refer to another professional. Focusing on existential, spiritual, and religious needs, a referral to a psychologist or a chaplain might be the most relevant. However, a referral requires that the physicians ask initially about these issues to be able to identify the patients who would welcome a referral; a solution many doctors are reported to prefer (Best et al., 2016). Patient-centeredness with shared decision-making is intended to improve health outcomes (Epstein, Fiscella, Lesser, & Stange, 2010). Moreover, if dealing with existential issues is not accomplished, practicing shared decision-making may give the physician a false sense of having met patients' subjective needs. Seen from the original vantage point of patient-centeredness, meeting these needs requires a trustworthy relationship in the encounter.

The relationship in the encounter

To approach the different disease-related needs demands a relational and more nuanced picture of the physician–patient relationship as also evident in the original historical definition of patient-centeredness (Balint, 1957, 1969). Here, the physicians are supposed to address the patients' conscious and sub-conscious needs drawing on their medical expert knowledge and experiences (asymmetry) and on the relationship between the physician as a person and the patient as a person (symmetry) (Balint, 1957; Balint, 1969).

Existential, spiritual, and religious needs might be sub-conscious for some patients, while others might hesitate to address all their conscious needs. Thus, practicing from the original understanding of patient-centeredness opens an opportunity for the physicians to ask patients about these needs and ways to make meaning in life regardless of patients' own initiative (Roessler & Lindemann, 2014). As an expert in a specific chronic disease, the physician can address how patients cope with the possible challenges of living with a chronic disease and as a person engage in the relationship with the patient and listen to the possible disease-related existential concerns the patient might experience. On the other hand, even though patients with chronic illnesses experience illness-related existential, spiritual, and religious needs, it might be that patients would not want these questions to be addressed or that they would like them to be addresses by other health care professionals than the physicians. A systematic review of 54 studies showed mixed results about patients' preferences regarding discussing spiritual and religious themes with their physicians (Best, Butow, & Olver, 2015). The conclusion was that most patients thought it was appropriate for physicians to address spirituality and religion in some cases, because they saw it as strengthening their relationship to the physician and as providing more personalised care (Best et al., 2015; McCord et al., 2004). The interest increased with illness-severity regardless of religiousness (Daaleman & Nease, 1994; Ehman, Ott, Short, Ciampa, & Hansen-Flaschen, 1999). Patients who did not want the physician to address spirituality or religion were either not seriously ill (from general practice or an ophthalmology-practice) or preferred to discuss such issues with a clergy or a family member (Best et al., 2015). Although spirituality and religion were the key words for this review, 'existential' was used as a synonym for 'spiritual' in trial searches in the review, and no new papers were found. 'Spirituality' as a concept differed in the studies thus, in some studies, 'spirituality' comprised an existential perspective such as a dimension in humanity and finding peace and meaning in life. It seems that patients would like physicians to address existential, spiritual and religious issues, due to the relationship and a wish for a more personalised care, especially in circumstances of severe illnesses; and when they did not want their physician to enquire, they either were not seriously ill or would not prefer this type of care from a health care professional.

Another discussion regarding physician–patient communication around existential, spiritual, and religious themes and needs, refer to the interference of the physicians' private characteristics with their professional approaches. There seem to be a tendency that the degree of the physicians' own commitment or non-commitment to spiritual or religious stands in life correlates with the degree in which the physicians address these themes in the encounter (Curlin, Chin, Sellergren, Roach, & Lantos, 2006; Olive, 1995). However, regardless of the health care professionals' educational background, clinical recommendations stress the ethical importance of neither posing own attitude or meaning system on the patients, nor judging the patients' existential, spiritual, or religious stand in life but instead protect the boundaries of appropriate professional behaviour (Betancourt, 2003; Gonsiorek, Richards, Pargament, & McMinn, 2009; Poole & Cook, 2011; Stone & Moskowitz, 2011).

In our material, the healthcare-system's focus on treatment as a service rather than trust is criticised. This echoes studies criticising the uncaring space in the hospitals (Carr, 2010) advocating for a focus more on the person than on the patient (Røysland & Friberg, 2016; Starfield, 2011). Some of the physicians in our study apparently managed this dilemma by

using their personal experiences to attend to the patients' needs, thereby using the original understanding of patient-centeredness as being both an asymmetric and symmetric relationship. In these physicians' experiences, it was significant for the patient's treatment, wellbeing, and experiences with the healthcare system that the physician did not only attend to the immediate challenges but could also 'see behind', address, and listen to the patient's existential concerns; furthermore, this approach was experienced as time-saving. The physicians' use of the original understanding of patient-centeredness might reflect a shift from the view of treatment as something to be delivered in the relationship to the relationship itself being an important part of treatment (Adler, 2007).

From a relational, psychological perspective, a physician's communication in the encounter is expected to be contingent on and influenced by the physician's personal background, biomedical training, and experiences in constant interaction with the patients' personal background and experiences (Andersen, Assing Hvidt, Hvidt, Illés, et al., 2019). If patients have spiritual and religious needs and need to deal with existential challenges of identity and death, as experienced by the physicians in our study, meeting these might be significant for treatment and how to live with a chronic disease; moreover, to be able to discuss these needs, patients need a trustworthy relationship with the physician. As the physician-patient relationship in general impacts health outcomes, effects on patients' health might be negative if the physician-patient relationship cannot contain patients' disease-related existential crises and associated coping-strategies and needs (Dezutter et al., 2016; Zachariae et al., 2003).

In our material, the existential challenge of death, understood as fear of death and suicidal thoughts about death, is an example of a significant existential issue that must be catered for in treatment. For some of the physicians in this study, the encounter was experienced as a room for alleviating distress related to the life with a chronic disease, thereby constituting a vital foundation for treatment and care. In the late nineteenth century, the Canadian physician William Osler brought these matters to a head by saying: 'It is much more important to know what sort of a patient has a disease than to know what kind of a disease a patient has' (Sturmberg & Martin, 2009). It reveals an approach where the physician, to really help the patient, meets the patient as a personal subject rather than an object (Buber, 1923/1997). Thus, our study suggests that attending to existential, spiritual, and religious needs in the encounter requires a relation with the possibility of addressing both conscious and unconscious needs from a personal, empathic perspective. Moreover, this relational approach seems to be pivotal for treatment of chronic illnesses (Andersen, Assing Hvidt, Hvidt, & Roessler, 2019; Vang et al., 2019) and even more so in countries with a cultural experience of privacy regarding these needs (Assing Hvidt, Søndergaard, et al., 2017; Rosen, 2009).

The cultural experience of privacy

Just as personal interest and experience paved the way for addressing patients' needs, a personal feeling or experience of privacy regarding these needs became a barrier. The physicians in our study seemed to be enrolled in a culture indicating which subjects to focus on and which subjects to consider too 'holy' or too intimate to be addressed. In other aspects, physicians' work encompasses very intimate parts of a patient's life, as for example intimate body parts or queries about sexual problems related to disease and

medication, wherefore it is interesting why existential, spiritual, and religious needs are viewed as specifically private and even 'holy'. Considering the surrounding culture, the view of privacy might be rooted in a lack in their medical training and may also be a part of the Danish culture as such, where religion is considered one of the most tabooed subjects (Hvidt et al., 2018). From a sociological perspective, physicians are always embedded not only in current medical culture but also in the surrounding culture of society (Berger & Luckmann, 1966/1996). In this study, the surrounding culture is that of a society characterised as secular (Taylor, 2007; Zuckerman, 2008) and, according to one of the physicians' experiences, a private approach in general to personal feelings and experiences. Further cultural influences might be the expectations from society to the characteristics of the physicians and how physicians enact their roles (Parsons, 1951). If existential, spiritual, and religious needs are considered too holy or intimate, and if physicians are expected to enact a secular value system, communication about these needs in the encounter is challenged.

Although physicians differed in their approach to the existential, spiritual, and religious needs, they did agree that a chronic illness influences the patients' life in a way that often leads to an existential crisis, and all of them expressed an openness towards meeting their patients' pro-actively verbalised needs. This resonates with findings from a general practice setting in which general practitioners characterised themselves as constituting the main barrier to addressing existential and spiritual patient needs in medical care (Assing Hvidt, Søndergaard, et al., 2017). Due to the medical culture and lack of educational knowledge and professional training, the physicians in our study either drew on their personal experiences and interests or avoided addressing these needs. Therefore, further training in how to address these needs in the encounter is warranted.

Methodological considerations

This study was conducted with physicians specialised in the treatment of chronic pain and multiple sclerosis. The transferability of these findings may therefore be highest for treatment of other chronic diseases running a severe, non-life-threatening course.

Furthermore, the physicians were enrolled in a healthcare system characterised by Western medicine's focus on the objective, individual body separated from subjective and religious ways of understanding sickness and health, which might limit the relevancy of the findings for physicians enrolled in healthcare systems with a less westernised, more pluralistic approach.

A significant limitation in our study – beside the limited number of involved physicians – might be, the lack of an explicit comparative study (between chronic pain specialists and neurologists). Potential unmeasured confounders may therefore not equally be distributed. The included physicians were selected by their accessibility based on their different experience and not chosen with specific focus on gender or age. Another limitation may be the duration and cadence of the interview process since conducting two interviews with each physician could allow the physicians to reflect on the themes derived from the first interview in relation to own practice before the second interview. This may provide more in-depth knowledge; however, such an approach should also imply asking the physicians if they were aware of any changes in their approach since the first interview, and a reflection of the possible bias herein.

Conclusions and future study

Specialised physicians experienced that some patients expressed spiritual and religious needs, whereas all their patients with a chronic disease had existential needs. They did, however, not regularly address these needs unless they had a personal interest in doing so. Medical training and the paradigm of patient-centeredness including shared decision-making seem to be barriers for existential care together with a Danish culture of privacy regarding these needs. Since patients' preferences in situations with severe illnesses seem to be either that the physician should address the existential, spiritual, and religious needs, or that friends or a chaplain should, physicians might initially address these issues to determine who would welcome a referral. The present article argues that the physicians' approach is well suited to meet the objective, concrete, and conscious needs of their patients but might be challenged by patients calling for a relational meeting with a focus on their subjective lifeworld.

There might be negative implications for patients' health and well-being deriving from this hesitant approach towards their existential, spiritual, and religious needs, but research is needed to study what such potential neglect might entail for patients' health. A next step will be to develop a guideline to approach these needs based on patients' perspectives and to evaluate physicians' training in how to include subjective needs in a professional, interpersonal approach in the medical encounter. Such studies can pave the way for implementation of the scientific re-discovery of the relationship between spirituality, religion, and health into clinical practice to further enhance treatment of chronic diseases.

Note

1. The brackets indicate a clarification added by the first author.

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Ethics statement

Our study follows the principles of the Declaration of Helsinki.

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