Patient versus health care provider perspectives on spirituality and spiritual care: the potential to miss the moment

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Background: Spirituality and spiritual care are well recognized as important facets of patient care, particularly in the palliative care population. Challenges remain, however, in the provision of such care. This study sought to compare patient and health care professional (HCP) views on spirituality/spiritual care, originally with a view to exploring a simple question(s) HCP's could use to identify spiritual distress, but evolved further to a comparison of how patients and HCPs were both concordant and discordant in their thoughts, and how this could lead to HCP's 'missing' opportunities to both identify spirituality/spiritual distress and to providing meaningful spiritual care.

Methods: Patients (n=16) with advanced illnesses and HCP's (n=21) with experience providing care to those with advanced disease were interviewed using a semi-structured interview guide. Qualitative analysis was performed and responses were compared under specified categories (definitions of spirituality, spiritual distress and spiritual care, and screening for spiritual distress).

Results: Within each category there were areas of both concordance and discordance. Most notably, HCP's struggled to articulate definitions of spirituality whereas patients generally spoke with much more ease, giving rich examples. Equally, HCP's had difficulty relating stories of patients who had experienced spiritual distress while patients gave ready responses. Key areas where HCP's and patients differed were identified and set up the strong possibility for an HCP to 'miss the moment' in providing spiritual care. These key misses include the perception that spiritual care is simply not something they can provide, the challenge in defining/ recognizing spirituality (as HCP and patient definitions were often very different), and the focus on spiritual care, even for those interested in providing, as 'task oriented' often with emphasis on meaning making or finding purpose, whereas patients much more commonly described spiritual care as listening deeply, being present and helping them live in the moment.

Conclusions: Several discrepancies in perception of spirituality, spiritual distress and spiritual care may hinder the ability of HCP's to effectively offer meaningful spiritual care. A focus on active listening, being led by the patient, and by providing presence may help limit the risk of a disconnect, or a 'miss', in the provision of spiritual care.

Keywords: Spiritual care; spiritual distress; palliative care

Introduction

The provision of spiritual care, especially at end of life, is seen as vitally important in the provision of quality care. Spiritual pain felt by patients and family members impacts on many aspects of the illness experience including physical and emotional symptoms, social relationships, and quality of life (1-5).

The World Health Organization has identified spiritual care as a core domain in patient care and evidence based national standards on palliative care emphasize the necessity of providing spiritual care (6-8). Yet a variety of authors have described unmet needs regarding spiritual care, despite the strong support for the presence of existential distress and suffering in patients with life threatening conditions (8-14).

Meeting the spiritual care needs of patients and family members necessitates all health care providers have some degree of proficiency in this domain (11,15,16). However, front line practitioners have expressed difficulty recognizing spiritual distress, engaging in discussions about spirituality with patients or family members, and being clear about their role in providing spiritual care (17,18). Additionally, busy clinical environments contribute to the challenge with increasing patient workloads and shortened intervals with individual patients. Although the recognition and acknowledgement of spiritual distress in an individual is a key step in providing spiritual care, it is a challenging process in itself (10,19).

Our work began with a focus on identifying whether there was a screening question or questions that would allow the front line worker to reliably and validly identify spiritual distress in an individual with a life threatening condition. The work unfolded in two stages: interviews with patients with advanced illnesses, and interviews with health care providers caring for this patient population. This article will focus on comparing the perspectives on spirituality and spiritual care from these two sets of interviewees with the subsequent implications for clinical practice.

Methods

Data collection

This study was conducted at Sunnybrook Health Sciences Centre (SHSC), a tertiary care hospital in Toronto, Canada between March and November 2014. Patients with advanced disease and a prognosis of less than 12 months were eligible for inclusion and were recruited from the outpatient palliative care clinic, inpatient acute care wards

and the palliative care unit. Eligible HCPs included licensed physicians, nurses or social workers who routinely cared for patients with advanced life-limiting illnesses. Physicians and nurses were individually invited to participate, while social workers were invited during a routine team meeting. Consenting participants engaged in an in-depth semi-structured interview by an experienced interviewer. Separate patient and HCP interview guides were developed and used to explore participant's views on spirituality, spiritual distress and spiritual care. All interviews were audio-taped and later transcribed verbatim. This study was approved by the SHSC research ethics board (No. 439-2013), and all participants provided written informed consent.

Interview guide

The interview guides were developed by the research team to explore participant perspectives on spiritual distress. Questions were chosen to elicit participant views of spirituality, experiences with spiritual distress and spiritual care, and to provide insight into approaches and questions that might be used to identify/address spiritual distress. The research team reviewed the guides after the first several interviews to ensure the content elicited matched the goals of the study.

Qualitative analysis

The verbatim transcripts were subjected to a qualitative descriptive analysis (20) with patient and HCP transcripts initially analyzed separately. For each group, members of the research team read through several transcripts making margin notes about the content and subsequently agreed upon a list of topics or content categories for coding. All transcripts were then entered into NVivo9 (QSR International) software and coded by one individual using this agreed upon coding framework. The HCP transcripts were further analyzed by three authors (D Selby, D Seccaraccia, M Fitch) and the patient transcripts by five authors (D Selby, D Seccaraccia, M Fitch, J Huth, K Kurppa). Within the key domains identified, clear areas of commonality and difference emerged between patient and HCP responses with implications for clinical practice. Subsequent discussion among the investigators, comparing and contrasting their independent observations, resulted in the identification of themes within 4 major topic areas where HCPs and patients appeared to have important areas of both agreement and disagreement in responses:

"Definition of spirituality", "Definition of spiritual distress", "Definition of spiritual care", and "Screening process". This paper reports on these areas of concordance and discordance.

Results

Healthcare providers

In total 21 healthcare professionals participated in the study, including 8 physicians, 7 registered nurses, and 6 social workers. Nurses, physicians and social workers worked in inpatient and outpatient settings in oncology, internal medicine and palliative care. Participants had a minimum of one-year experience working with people with advanced end-of-life illness, but the majority had in excess of 5 years' experience. The majority of healthcare providers were female.

Patients

Twenty-three patients were approached, of whom 16 ultimately participated in the study (3 refused, 2 were too unwell and 2 died prior to the interview). Eligible patients had a diagnosis of a significant, advanced illness and a prognosis of less than 12 months as determined by the palliative care consultant providing regular care.

Topics

Topic 1: definition of spirituality
HCP's and patients had areas of commonality in their definitions of spirituality but also areas of significant contrast. Both groups spoke of spirituality as being unique to each individual and including personal values and beliefs. Both also identified formal religious beliefs as an important component of spirituality though recognized that spirituality could exist outside of a formal religion. HCPs were more likely to describe these as clearly dichotomous groups whereas patients tended to flow back and forth more readily between 'religion' and 'spirituality' as if they existed as a continuum.

In reviewing the transcripts, one of the most notable findings was the relative ease patients had in describing spirituality whereas the HCP's often struggled to express their thoughts, though clearly acknowledging the importance of spirituality. Further, patients repeatedly referred to their senses as they described spirituality,

covering all of taste, touch, smell, sight and hearing, whereas this was not mentioned by any HCP. Patients frequently referred to 'living in the moment' and appreciating the immediate, small things in life as part of their spirituality, which they acknowledged as having developed over the time of their illness. In contrast, HCP's had a greater focus on spirituality as finding meaning, making sense, or finding purpose, which was strikingly less common in the patient descriptions (*Table 1*).

Topic 2: definition of spiritual distress
Patients and HCP's had more areas of concordance when describing spiritual distress. Both groups described spiritual distress in terms of words such as isolation, loneliness and a sense of disconnection. For both, these terms related to their relationship with others around them (e.g., family) as well as their religion (i.e., disconnected from God). Negative emotions such as fear, guilt and despair were also used by both groups, as was the sense of questioning 'why me'. Not surprisingly, HCPs tended to speak more to visibly detectable behaviors such as questioning and emoting, while patients described internal, experiential distress often with a focus on powerlessness and a lack of control. Patients had no difficulty providing rich examples of spiritual distress while HCP's struggled to identify specific examples from their practice. Neither group found differentiating spiritual pain and spiritual distress to be meaningful and most replied with confusion when asked about the difference, tending to say pain was perhaps more intense (*Table 2*).

Topic 3: definition of spiritual care
In discussing spiritual care patients and HCP's again had areas of both concordance and discordance.

Concordant concepts included the key aspect of listening and being 'with' the patient, which HCP's often referred to as 'whole person care'. Both referred to the sense of someone 'taking on' the burden for the patient and both highlighted the importance of family as critical for spiritual care. For each group formal religion and the comfort it provided was also identified as important.

Areas of difference largely focused on who should provide spiritual care. HCP's, while acknowledging its importance, only rarely saw spiritual care as within their domain, for reasons related to expertise, comfort and practical concerns such as time. The almost uniform response from HCP's was to refer to chaplaincy, though some did mention the importance of calling on family. Patients, on the other hand, were quite broad in their thoughts of who provided

Table 1 Definition of spirituality

Topics	Healthcare professionals	Patients [participant number]
Compare		
Unique to the individual	"The definition of spirituality is very subjective to interpretation for different individuals."	Well there are so many interpretations for that. I mean, I don't really take into account anyone else's interpretation. I think it is a personal thing [6]
Formal religious beliefs as part of spirituality	To me, spirituality is defined as an inner belief system in terms of your relationship with a higher power. I'll call that higher power God. So it means your relationship with God.	Spirituality to me as far as I'm concerned is a connection with the spirit of God [2]
		"I think it doesn't matter which religion you belong to or believe, but faith is universal. I think to me, that's what spirituality means" [9]
Contrast		
Patients described their spirituality more readily, while many healthcare professionals struggled with the concept of spirituality	"And I find that it's a very nebulous concept. Um… you know, I think I have good labels, or I know what I mean when I use other words… um, I feel like I can have a very…um…er, compassionate interaction with patients and families. But the actual concept of spirituality is one…I personally find quite challenging…"	"It's a long and broad subject. Spirituality to some can be religion. Spirituality can mean the science of being human. What does that involve? What's your driving force within?....For me, spirituality is the science of learning what it is to be human and what our abilities and capabilities that we rely on to help us get through our day to day living" [8]
		"How they feel about themselves, about afterlife, about God, about their own individuality and who they think they have been in their life, their fears that are 'Have I done enough? Haven't I done enough? Am I going to do enough? Am I going to have the time to do enough? And what I've done already, is it acceptable?" [12]
Patients referred to their senses when they described spirituality, whereas healthcare professionals focused greatly on belief systems and looking for answers	"Spirituality is identification with a certain religious or other belief system. I don't think it has to be certain (like, an organized religion per say)…" I think it's ascribing to a certain value system, belief system which helps, you know regulate someone's hopes, desires and the way they live their life	"I'm sitting in the sun. I'm looking at the sky. I'm listening finely to the birds…To me that's at peace." [12]
		"You have to look around and see and smell and taste, and touch all the things that are here for you that you take for granted so often."[3]
Patients described living in the moment and the small things, whereas healthcare professionals described meaning-making and finding purpose	"I think spirituality helps them get a sense of meaning and connection with their loved one as well as with the overall universe in regards to the situations they are going through."	"You just smell the lilacs and think 'isn't that magnificent'" [3]
		"I don't look forward for tomorrow. Like I live every day. I live day by day and this keeps me going" [14]
	"Spirituality is in part looking at trying to find an answer as to why this has happened…..to try to find meaning in something."	"Enjoy what the day brings you today and that's it" [15]
		"So I appreciate those things more now. You take note of what's going on around you more" [12]

spiritual care, having it encompass anyone with whom they felt heard and understood, which in turn, left them with the sense of connection, otherwise missing in spiritual distress. The importance of 'feeling connected' was highlighted significantly more by patients than HCP's in their descriptions. Interestingly, some patients did note they were not sure if they would be comfortable with their health care providers asking about spiritual issues, noting that this required a sense of relationship as a first step (*Table 3*).

Topic 4: screening process for spiritual distress
Healthcare professionals and patients were in agreement

Table 2 Definition of spiritual distress

Topics	Healthcare professionals	Patients [participant number]
Compare		
Isolation, loneliness and sense of disconnection	"So I think the whole concept of distress is often a disconnect between expectations and reality and what to do with those two kinds of confounding issues."	"A feeling of separation, loneliness." [1]
		"Spiritual distress would be lack of spiritual connection. Like at that moment I couldn't grab onto anything for help. There was nobody there to help……the distress is being totally alone." [3]
	"A sense of suffering"	
	No matter how much love and support you have in your life this is something you are ultimately doing on your own	"I think spiritual distress would be separation" [6]
		"Spiritual distress I believe to me is a disconnect with your faith, with your religion." [7]
Negative emotions such as fear, guilt and despair, and the sense of questioning 'why me?'	"Fear of death, loneliness, social isolation, guilt. All those factors come into play."	"I am scared and I don't know what to do." [3]
		"Why did God do this to me?" [1]
	How could this be happening?	"I'm not above having certain emotions; I expressed anger and I felt anger. " [13]
	"…So when I think about it with respect to healthcare and disease, to me, spiritual distress would be that you question why something is happening to the point that your faith in a higher power goes down."	"Why me? I'm a good person. Why have I got this cancer?" [15]
Differentiating spiritual pain and spiritual distress was not meaningful and confusing	"Spiritual pain? I'm not exactly sure. Like, I'd have to think about—I can understand spiritual distress. Like, I can kind of conceptualize it but I can't conceptualize spiritual pain."	"I have no idea what spiritual pain is either." [1]
		"Distress? And spiritual pain? Yeah, are those terms different or are they similar? I would imagine that they would be connected." [16]
Contrast		
Healthcare professionals struggled to provide examples from practice; meanwhile, patients eloquently described their own examples of distress	"You know I remember some cases where a woman did confide to the team that she felt that God had let her down. Or, her…her spiritual community…um…had not stepped up to address her spiritual distress. You know, the "why me?" questions, things like that."	"I see an absence of anything positive. Your life has gone out of control and you can't summon any number of earth angels or other angels to help because they can't." [3]
		"The darkness. You're in a darkness and you want to come out. You're crying for help." [11]

that the screening process is one that requires a conversation and is unlikely to be captured by one or two simple, uniform questions. While patients offered a number of suggestions for opening the topic they also acknowledged that the time and situation needed to be appropriate. Patients were not sure it was a topic that could be approached too directly and some noted that amidst a crisis was likely not the right time. HCP's tended to focus more on whether identification of spiritual distress was even within their domain of care (*Table 4*).

Discussion

Spiritual care is well recognized as an important component

of patient care particularly for those with advanced illness (2,5,11,21,22). To provide such care, however, it is important that we understand both patient and HCP perspectives on spirituality and spiritual distress and how these perspectives both align and differ. This study was originally designed to develop a screening question to allow ready identification of spiritual distress by front line HCP's but what emerged instead, was a number of important areas of concordance and discordance in how patients and HCP's viewed both spirituality and the care of spiritual distress.

Interesting areas of contrast were notable in definitions of spirituality with patients highly focused on sensory experiences and living 'in the moment' rather than limiting spirituality to belief systems and 'answers', though

Table 3 Definition of spiritual care

Topics	Healthcare professionals	Patients [participant number]
Compare		
Whole person care, listening and being with the patient	"I think it is part of you caring for the person as a person. So I'm not coming in and caring for you as the appendectomy. I'm caring for you as the whole person."	"It's like taking the burden on yourself and helping them to bear the burden. That's spiritual care." [16]
	"There is a lot of listening that comes with the talk about spirituality."	"Just listen. You'd be surprised to know what you pick up… "what would they be listening for?"…hints about how the person is really feeling." [13]
	"I open the discussion and ask them, you know, what would help you at this moment?"	"Oh, spiritual care is just—I guess simple term I would use is just respect. It's just—yeah, just simple respect would be the first step…..If you respect the reaction of the person you can reinforce where they are coming from. Which is all that really matters." [6]
Family as critical for spiritual care	"If they would ask for a person in particular to call a family member, to call a friend, to call anybody. To—you know, whatever it is (I would help them). I would help to meet their spiritual need."	"Taking care of the family and the family taking care of me and carrying so much…" [12]
		"My family as well. I have my children and my husband. They are around me. They give me a lot of strength." [11]
		"…we can't be relying on doctors and nurses to do this job. You know, there has to be an involvement of a community." [8]
Contrast		
Healthcare professionals had a tendency to refer to chaplaincy, while patients wanted to be heard and understood	"I guess I just don't see that as a job I could do as well as probably other people. Be it other well trained palliative care physicians or, you know, people from Chaplaincy or spiritual care providers."	"She listens. She truly listens. She does listen. You can talk all you want. There are certain doctors that are hearing what you are saying but are truly not hearing or listening. You know….she really truly listens to what you are saying." [11]
	"I would tell them about Chaplaincy, or call Chaplaincy"	"…the power of listening. It's so incredible." [7]
		"I do have this conversation but it's got to be with people who understand, and are not going to judge or criticize…listen to what you say…"[6]
		"Well it is just to be with what you are feeling."[8]
Importance of feeling connected was highlighted more by patients than healthcare professionals		"…somebody whose job it (is) to connect with (a) person…" [3]
		"So that human connection then is important." [8]
Some patients were uncertain of their comfort level of healthcare professionals asking about spiritual issues, meanwhile some healthcare professionals discussed time and financial constraints preventing them from providing adequate spiritual care	'And I know listening and acknowledging are intervention in themselves, but you're not going to open up that conversation in a short period of time."	"It's not something people want to talk about anyway (I don't think) because it is very personal. If my doctor asked me, 'are you feeling/experiencing spiritual distress?' I don't know if I would even want to hear that question."[2]
	"When they come in for clinic they are here for 10–15 minutes max. How do you be effective in recognizing it and providing some intervention or referral in a short period of time with everything else going on around."	

Table 4 Screening process for spiritual distress

Topics	Healthcare professionals	Patients [participant number]
Compare		
Requires a conversation, and unlikely to be captured by one or two uniform questions	Maybe it is a matter of starting a bit of a screening process but I think a lot of it is always addressing the culture of speaking of these things. That's a bigger venture.	"They ask it every day, 'how are you feeling?' but do they take the time to stop and listen to what [the patient] said…" [8]
	I like to have these conversations over time because I don't think thy can happen over one visit or one hospital admission. They need…you open the conversation….	"We had some good conversations. I felt so – just so in his care. It was beautiful." [4]
	'So I think that starts the conversation'	
Contrast		
Patients offered suggestions for opening this topic, whereas majority of healthcare professionals did not know how to ask	"I could do a…I could ask about suffering, I could ask about distress in the general sense, but spiritual distress? I am not sure I have the right words to even get at that information."	"Is there something I can help you with? It looks like you are searching for something and you are not sure where to find it." [16]
	"It's really—it's hard for me to think of anything better than, 'would you like to speak with a Chaplain?'"	"How can I help today?" [8]
		"I'd ask them if they were alone. If they felt alone." [6]
Patients acknowledged that it was not a topic to be approached too directly or amidst a crisis; meanwhile, some healthcare professionals dismissed spirituality as part of their role or was inappropriate to ask about	"So, you know, we certainly are there to support them but we really can't introduce the question or ask what we can do for them spiritually."	"If somebody had asked me that night, 'Are you in spiritual distress?' I probably would have screamed at them." [3]
	"Like I said, I don't—the explicit distress or what may be distressing people I don't think (in my role) is appropriate."	
	"I'm not—Like, I'm just not sure if you're asking everybody if they have spiritual distress. I mean, I don't want to freak people out too, right?"	

certainly patients spoke of a connection to a higher being and for many that was indeed an important component of spirituality. This focus on sensory experiences as a core component of spirituality was more prominent in our study than has been described in prior studies, which have highlighted to a greater extent the focus on meaning making described by patients. However, in her review of spirituality, Hermann (12) listed 'need to experience nature' (page 71) as one of the six facets of spirituality patients described. Similarly, Edwards meta-analysis (11) identified 'relationship with nature and music' (page 759) as one of the relationships patients described as important. In general, our HCP's, unlike patients, struggled to easily define spirituality, though uniformly cited its importance, a finding consistent with prior literature (11,17). When defining spiritual distress, HCP's and patients were quite aligned in

their focus on suffering, isolation, and questioning 'why'. However, while patients had a broad sense of provision of spiritual care, essentially including anyone with whom they felt connected and supported, HCP's were generally uncomfortable with the thought of providing spiritual care and consistently described this as belonging in the domain of chaplaincy. Neither group felt there was an easy or quick way to screen for spiritual distress.

These data raise the possibility of significant 'misses' occurring in interactions between patients and HCP's, where patients may not feel heard or understood despite the best intentions of the HCP.

The first source of these potential misses lies in the consistent response from HCP's that spiritual care was simply not their role. Again despite the clear acknowledgment of the importance of spiritual

care, virtually all HCP's spoke of spiritual care lying predominantly in the domain of chaplaincy. Kalish *et al.* (23) in a review of the literature noted that HCP's tended to view spiritual care as part of their role to a much greater extent than they actually provided, somewhat in contrast to our findings where our participants acknowledged discomfort or inability to actually provide such care. Most expressed barriers including training, expertise, time and comfort with assessing for spiritual distress and providing spiritual care. Given patients expectations that any HCP can provide spiritual care by listening closely, attentively, and with a view to understanding the individual as a unique person and what was important to him or her, the fact that HCP's largely rejected this as their role presents an overwhelming risk of a 'miss' or disconnect.

The second clear 'miss' lies in the fundamental difficulty HCPs had in expressing concepts around spirituality. Lacking a clear concept of spirituality, or a clear sense of what might be embraced by individuals as a spiritual experience, HCPs may then fail to 'hear' when a patient is expressing their sense of spirituality. For example, patients focused on events occurring in the moment and sensory experiences such as 'smell the lilacs' or 'listening finely to the birds' that the HCP may simply not categorize or appreciate as a spiritual expression by the patient. This in turn, may result in the HCP missing an opportunity to explore spirituality with their patient or to understand if there is a sense of spiritual distress being experienced by the individual.

Finally, the third identified potential for a miss may occur when the HCP who is wanting or willing to provide spiritual care approaches it with a pre-conceived idea or agenda about what spiritual care is. HCP's, in discussing spirituality and spiritual care, often spoke of meaning making and finding purpose, a concept seldom actually expressed by patients. Despite good intentions, if HCP's approach a patient with this pre-formed concept of what spiritual care is supposed to be or what elements ought to be covered in an assessment of spiritual needs, there is the risk that the patient may instead feel dismissed or 'not heard' while the HCP may feel frustrated that their efforts are not successful. The sense of alienation and isolation can then grow, worsening the disconnect.

Patients very clearly focused on internal experiential feelings, be they deep feelings of distress or important feelings of comfort by seemingly small, in the moment, sensory experiences. Provision of spiritual care as defined by both patients and HCPs, did include listening and being

with the patient. HCP's though, with their bias towards problem solving and 'fixing, may be at risk of failing to hear the patient in a way that is meaningful and comforting. Active listening has been well described in the literature (21,24-27) as an effective tool to help patients in distress. Such listening implies being guided by the patient and acknowledging whatever feels important to them, without imposing pre-existing beliefs or having an agenda as to what the HCP views as important. As emphasized by Lemay *et al.* (28) 'the value of listening, and the use of silence, while withholding ones theoretical assumptions and personal experiences...' can allow 'for connection and dialogue to emerge' (page 488). Similarly, dignity therapy as described by Chochinov (29) encourages patients to express what is important to them. Puchalski (21) highlights in the report on a consensus conference the importance of HCP's listening to the patients' story, a concept further reinforced in Edwards meta-analysis of spiritual care (11). These approaches would all lessen the risk of any of the three described misses, as all assume spiritual care as in the domain of any provider who can be attentive, listen without an agenda, and 'be with' the patient.

Conclusions

Our study strongly reinforces the need to listen openly, being guided by the patient, to allow them to explore what is important to them, which in turn may help to alleviate their spiritual distress. While HCP's uniformly acknowledge the importance of spirituality and addressing distress, it is important that they not impose their own preconceived notions of what 'needs discussing' (e.g., meaning making, finding a purpose, answering why) but rather allow the patient to lead the way.

Limitations

This study was limited to English speaking patients well enough to participate in an interview. All HCP's were drawn from a single institution, and one with a strong chaplaincy program which may have influenced their perception of both their role and chaplaincy's central role in spiritual care. Both factors will limit generalizability.

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Footnote

Conflicts of Interest: The authors have no conflicts of interest to declare.

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