

Patient Perspectives about Spirituality and Spiritual Care

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ABSTRACT

Objective: This study was undertaken to explore the perspectives regarding spirituality and spiritual care held by individuals with advanced disease. The aim was to gain a deeper understanding about their viewpoints surrounding spiritual care and the role of health-care professionals in providing such care. **Methods:** Sixteen individuals with advanced disease and a prognosis of <12 months underwent an in-depth interview. Transcripts were subjected to a qualitative descriptive analysis to identify salient content and themes. **Results:** Four overall themes were identified: Spirituality is personal, spiritual distress is about separation, spiritual care is about connecting, and conversations about spirituality must align with the patient's beliefs. Subthemes emphasized the individuality of spiritual expression, the potential for illness impacting spiritual beliefs,

and the value of connections to one's spiritual community. Participants thought healthcare providers needed to be able to identify individuals who were experiencing a spiritual struggle, acknowledge the reality of that struggle, and connect the individual with the appropriate resource or person. **Conclusions:** Patients with advanced disease are likely to express their spirituality in unique ways. Being able to talk about their spiritual beliefs and doubts during illness without judgment was seen as a benefit to them. Healthcare providers ought to be able to identify those patients who require assistance in connecting to appropriate spiritual care resources.

Key words: Advanced disease, patient perspectives, spiritual care, spirituality

Introduction

An individual facing advanced disease experiences more than a physical impact. There are social, psychological, spiritual, and practical consequences as well.^[1,2] One consequence that has received less attention relative to the others within health care is spirituality. However, over

the past decade, there has been an increasing interest in spirituality as part of supportive care and quality of life priorities, especially for individuals living with advanced disease.^[3-6] Providing spiritual care, or attending to the spiritual needs of patients, is now identified as a core

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domain in patient care by the World Health Organization,^[7] and guidelines and standards on palliative care emphasize the importance of incorporating spiritual care into daily practice.^[8-10]

Many studies have documented unmet spiritual needs and illustrated existential suffering, spiritual distress, and spiritual pain in patients with life-threatening illness.^[11-19] Harrison *et al.*^[1] reviewed 94 supportive care needs studies and reported between 14% and 54% of cancer patients indicated through survey responses that they had unmet spiritual needs. The spectrum of spirituality encompassed spiritual despair (alienation, loss of self, and dissonance), spiritual work (forgiveness, self-exploration, and search for balance) and spiritual well-being (connection, self-actualization, consonance). When unmet, spiritual needs can have a profound impact on symptoms, social relationships, quality of life, and well-being.^[20-30] In addition, spiritual concerns can influence decision-making about treatments^[31-32] as well as coping and adjustment to illness.^[33-35]

Despite healthcare professionals acknowledging the importance of spirituality and of providing spiritual care,^[36-38] practice patterns vary in relation to engaging in spiritual care.^[23,34,39-42] Front-line providers report they have difficulty identifying when a patient is experiencing spiritual distress, having relevant discussions about spiritual needs, and knowing when a referral to chaplaincy is appropriate.^[43-46] Personal discomfort, lack of knowledge and skills in spiritual care, lack of role clarity and models of care, training and time, and ever-increasing demands of busy clinical environments have been cited as barriers to engaging in spiritual care.^[47-50]

Concern about the variation in delivering spiritual care emerged in our clinical setting as part of implementing a person-centered approach to patient care.^[51] As a primary step before developing and refining services to address this concern, and in accordance with a person-centered approach, we undertook to explore the perspectives of individuals with advanced illness about spirituality and spiritual care. Ultimately, we hoped to gain a deeper understanding about their views surrounding spiritual care and the roles of health care providers within the context of their own conceptualization of spirituality and illness. Although investigations have focused on perspectives regarding spirituality,^[52-54] there remains little consensus on the definition of spirituality in illness^[31,55-56] and wide variation in how it is operationalized as spiritual care.^[23,57-61] In addition, few studies describe patient perspectives about spiritual care itself.^[62-64]

Methods

The study utilized a qualitative descriptive design and was conducted at Sunnybrook Health Sciences Centre.

Ethics approval was granted by the hospital's Research Ethics Review Board before beginning of data collection.

Eligibility and data collection

Patients with advanced disease and a prognosis of <12 months were eligible for inclusion. Individuals were recruited from the outpatient palliative care clinic, inpatient acute care wards, and the palliative care unit. The most responsible physician spoke to the patient initially about the study and for those who agreed, the research coordinator subsequently contacted the individual to fully explain the study and obtain consent.

Consenting individuals engaged in an in-depth semi-structured interview, in person or over the telephone, conducted by an interviewer with extensive experience in qualitative research. All interviews were audio-taped and transcribed verbatim.

Interview guide

The interview guide was designed for the purposes of the study by a group of physicians (palliative care expert, psycho-oncology expert), hospital chaplains (2), social workers (2), and nurse researcher. All had expertise in the area of spiritual care for individuals with a life-threatening illness. Questions were crafted to gather patient perspectives about spirituality, experiences with spiritual distress and spiritual care, as well as to provide insight regarding how spiritual distress can be identified and acknowledged by front-line staff members. The guide was reviewed after the first several interviews to ensure the questions were clear for participants; no changes were made to the questions.

Analysis

The transcripts were subjected to a qualitative descriptive analysis.^[65] Members of the research team individually read through several transcripts making marginal notes about the content. Through subsequent discussion about the content, the team members reached agreement regarding a list of topics or content categories for coding (i.e., coding framework). The transcripts were then entered into NVivo9 (QSR International) software and coded by one individual using the agreed-upon coding framework. The content in each of the coded categories was subsequently reviewed individually by team members to identify key ideas. Subsequent discussion together about the key ideas resulted in the identification and agreement regarding the final themes reported below.

Results

Selected demographic information

A total of 23 individuals were approached to participate in the study, of whom 16 underwent an interview. Three

declined to participate, two became too unwell, and two died before the interview. All participants were diagnosed with a significant, advanced illness, and a prognosis of <12 months by the palliative care consultant providing regular care to the individual. Participants ranged in age from 58 to 93 and the majority were female. Twelve individuals indicated a Christian background (6 = Roman Catholic, 5 = Protestant, and 1 = Jehovah's Witness), two indicated new age/mysticism associations, one indicated following Buddhism, and one indicated being a non-believer.

Themes

Four themes emerged from the analysis of the data. Each will be described below and illustrative quotations for each can be found in Table 1.

Theme: Spirituality is personal

Participants spoke about spirituality in a range of individual ways illustrating their unique perspectives by describing their personal values, beliefs and faith. All but one (i.e., nonbeliever), spoke clearly, and strongly about their beliefs associated with their respective religious communities and described how they engaged in their religious practices of prayer, meditation, reading of scriptures and other religious material, singing worship songs, and gathering with other members of their community for various events (i.e., services, prayer group, and Bible study). Most described a long-term commitment to their religion and beliefs, a sense of personal relationship, and how supportive it felt to be together with others who held the same beliefs.

In defining spirituality, these participants talked about having a personal connection or relationship. In the case of the Christians and Buddhist, the relationship was with a Higher Being (i.e., God, Buddha) while those who ascribed to a new age/mysticism philosophy spoke about a relationship with the world and environment. For all, the relationship provided an avenue through which they experienced comfort, strength, and hope, particularly in times of difficulty. Some spoke about not fearing death and being able to accept what was happening to them because of their personal relationship and set of beliefs. The two individuals who held new age/mysticism beliefs indicated they gained comfort through spending time in nature and with family.

Participants acknowledged a shift in their spiritual beliefs since their diagnosis and illness. Most had experienced a deepening or a strengthening of their faith and beliefs since they had been facing life-threatening illness and in many cases, an increase in certain practices (i.e., prayer, reading of scriptures). Some found they had become more aware of the world around them and focused on the present: "making

sure I am fully here in this moment." In addition, some participants found they wanted to focus on the positive and not dwell on negative things.

Theme: Spiritual distress is about separation

Participants hesitated in describing the idea of spiritual distress as they were more familiar with using the words spiritual doubts or struggle. Overall, participants talked about separation and disconnection as the primary experience of a spiritual struggle. To feel separated from one's relationship with God, separated from one's beliefs or practices related to those beliefs resulted in feelings of upset, despair, hopelessness, and loneliness. Participants spoke of people experiencing spiritual doubts feeling as though "no one can help me," "an absence of anything positive," "life is out of control and you can't do anything about it." Individuals may be experiencing a loss of faith or a sense of disillusionment and doubt about their faith. Some talked about letting themselves drift and finding they feel far away from God and not where they are supposed to be. In essence, they are 'on the wrong path and feeling disconnected' from what had been grounding them. One individual thought "spiritual emptiness" would be a better term to use than "spiritual distress."

Participants acknowledged they had experienced spiritual struggles during their illness. For most, the period of time they were initially facing the reality that something was wrong with their bodies but they did not know what was happening was a period of distress. Feeling uncertain about what was happening, not having information, and not being able to process what was going on created a sense of turmoil, upheaval, and panic: "everything is such a whirlwind." Others talked about continually trying to deal with side effects, but feeling very low energy to do so, was overwhelming and brought about a sense of despair. Some talked about repeatedly asking themselves, "Why is this happening to me? Why now?," but not having answers. Feeling there was no place or person to turn for answers was frightening and left a sense of despair. Finally, a few talked about experiencing a loss of their autonomy as disturbing.

Theme: Spiritual care is about connecting

Participants experienced difficulty describing the concept of spiritual care. For the most part, they initially talked about the support and comfort they felt through their relationship or connection with God or Buddha and "knowing what God wants you to do." Some added that a visit by a priest or hospital chaplain was a type of spiritual care, especially when they prayed with the person, listened to them, or talked about what was happening to them and their beliefs. The idea of listening without judgment and being gentle was emphasized as being helpful to patients.

Table 1: Illustrative quotes from participants

Themes	Sub-themes	Examples of illustrative quotes from participant interviews
Spirituality is personal	Individuals express their spirituality in unique and varied ways	<p>Christian</p> <p>When I think of spirituality I think of Jesus (of God). That's who I think of – absolutely comes to my mind. RR</p> <p>My relationship with my Savior (my Lord). Through a lot of prayer and reading of the Word is my main – and really drawing on him for everything...in here (hospital) especially. I have really, really noticed it (that, I just have to lean). I have to take everything in my life and just hand it over to him and trust him that he is the one that is dealing with this. It's not me. It's him. I just put it all before him. I'm just relaxed in his love. I know he is there...GS</p> <p>It's about God. The closer you get to know him, the better you get to – when you know about God you get to be closer to him, more because you feel that the moment you tell him your problems and he answers...you feel that he is real to you...It's about personal relation to the one who created me. HS</p> <p>It's – anything spiritually I connect to the Lord, Jesus Christ. You know, we worship him as Christians...When it (diagnosis) happened to me, I didn't not think about taking the phone and calling my pastor. It was like, between me and God...It somehow helped me to understand the closeness of God, that I can approach him in this matter, and not go to a priest, or a friend. LA</p> <p>Immediately you think about religion when you think about, you know, your commitment to, you know, religion in general. That's what comes to mind. You know...it goes all the way back to childhood. You know, it's something that is just so deep that...it has not only begun for me at this time of my illness. It came from a very, very long time ago...So you know, every time there is something that goes wrong, you reach out to God...That's my real viewing of it, really. KS</p> <p>I think it doesn't matter which religion you belong to or you believe to, but faith is (I would say it's) universal. I think to me, that's what spirituality means. Faith for me means a lot of strength. I get a lot of strength from prayer. LMA</p> <p>Well, without spirituality in my life, I could not live. I rely on the Lord for everything: the way I move, the way I make decisions. I always pray. MS</p> <p>People mention spirituality, I feel that it's their own personal belief in some power beyond this world. Everybody is – not everybody, but most people - have some type of spirituality in them. It's a belief in a greater power or something beyond their human being. PD</p> <p>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?" you know?. SG</p> <p>It's a long and broad subject. Spirituality to some can be religion. Spirituality, you know, can mean the science of being human. What does that involve? What's your driving force within? You know, how do you get in touch with that? For me, spirituality is the science of learning what it is to be human and what our abilities and capabilities that we rely on (how much credit do we give them to help us through) our day to day living. For me, it's really understanding the scope and breath of the life I live every day. LM</p> <p>New age/mysticism</p> <p>Well, there is so many interpretations for that. I mean, I really don't take into account anyone else's interpretation. I think it's a personal thing...I just accept what they say it is for them...Spirituality has no form or structure or bureaucracy (in my mind anyways)... if there is anything that is against spirituality would be separation. Though in my own life, I look at it as no separation between anything, actually. Everything is connected IS</p> <p>I guess you would consider it a little more new-age. So, I've been to mediums and heard from the other side as it were and believe that there are, you know, guardian people around us who watch over us. CG</p> <p>Buddhist</p> <p>For me it's like, you know, doing good to others...So, Buddhism is my faith. Yeah, and like, not harming other people and following with – that is spirituality for me...following Buddhism and a bit of Hinduism because we are influenced from where I come. We are Buddhists but it used to be like, a Hindu kingdom, so a lot of things influenced by Hindu rituals also... Our rituals are Buddhist but we also pray to like, Hindi Gods and stuff like that. AG</p> <p>Nonbeliever</p> <p>Listen. I have had so much to my life that I don't believe in spirit-stuff...I never went to – to – to church when I grew up because the people where I grew up, they wanted religions into us and that's when I say, "Oh, leave me alone. I don't want to have anything of this." HR</p> <p>Spirituality brings hope, comfort, strength and feelings of being supported</p> <p>...Because he made us, so he knows what's best for us. It's not in our hands. It's in his hands, whatever purpose he wanted for us...but at least in my religion, right now, we have hope. If I die right now, I have the hope to live again...I feel that the God that I am worshiping right now is real to me, not an image...I can confess my sin to him, and I know that he will forgive me. I can tell everything, just like a friend that I could trust. HS</p> <p>Me, I cannot imagine anybody without faith. Without faith, where do you get the strength to battle every day, because every day when you have this kind of disease is a battle, right? So, where do you get your strength, your inner strength if not from faith? Maybe not everybody needs faith. I don't know. I know, I do. LMA</p> <p>I'm never depressed...Because the Lord gives me help not to be depressed and to hope and trust in him and things will go all normal. I am strong enough to go on. MS</p> <p>Oh, definitely. I couldn't do it without my faith. I would commit suicide, that's all (without my faith). Life wouldn't be worth living. Well, because I would have no hopes in anything (in the Lord) so what's the use of going on? MS</p> <p>Well, it gives me confidence. When I was diagnosed with this grave illness that may take my life, I didn't get weepy or all upset. I was quite confident that if I did go, there is something more to go to. So, it gives me faith, and hope. PD</p>

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Table 1: Contd...

Themes	Sub-themes	Examples of illustrative quotes from participant interviews
		<p>I think of comfort. He takes away my pain. I think of being protected. That's what I think about when I think about my Lord...He gives me strength...I have no fears. RR</p> <p>Spirituality now to me is saying a prayer with my family, knowing how much they care for me and that their prayers are with me and knowing that no matter what I do now, I can't do any bad because the bad I've done, I've already done. So I'm here. Yeah. I don't live in the past anymore. It's not worth it. SG</p>
	Illness can impact spiritual beliefs	<p>Beliefs strengthen</p> <p>They've just made them stronger. Yeah. And even more positive (ironically)...I was, you know, sloping through life, taking everything for granted, and suddenly, I'm not anymore. I don't miss things. I pay attention. I have moments of, I guess, you'd call it 'quiet euphoria' where, oh, you just smell lilacs and think, "Isn't that magnificent?" That kind of thing happens. It just made it more solid (more positive). CG</p> <p>Drew me closer to the Lord. GS</p> <p>It's affirmed it for sure. Yeah, for me personally. Yeah, it's affirmed it. IS</p> <p>If you are faced with a disease like mine you know, you tend to go back to your faith more than when you are well. Like, I think it's human. LMA</p> <p>If anything it has made it stronger because I do believe as soon as I got ill that was the first thing that crossed my mind. This might be my time to go and that I am quite prepared...It gives me comfort because, instead of dwelling on the fact that something might go wrong, I just see it as part of life. We all know we live to die. – PD</p> <p>My faith increases every day because of the prayer I do...I feel closer to the Lord because of my illness. That's all I can tell you. He is with me. Jesus is with me. MS</p> <p>Focus shifted</p> <p>...But I'm looking in a different direction, you know, not just saying, "In the next month I'll be doing this "or – I'm not looking that far ahead. I've stopped looking that far ahead. LA</p> <p>If your life is limited, you've got to pay attention to every second you are on the planet. 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. (CG)</p> <p>Well, I like I went outside. I'm sitting in the sun. I'm looking at the sky. I'm listening finely to the birds. I haven't heard them for weeks and weeks. I go, where are the birds? To me, that's a peace. I can just sit there and, totally involved in it and connecting – I don't know if next week, next month, next year. I'm not going to be able to do that. SG</p> <p>Doubts raised</p> <p>Does it mean that I am disappointed with the Lord and my religions and everything else because I am not doing well? MS</p> <p>...Having the knowledge of the Bible and what spiritually (what spiritual information) you get from the Bible; then you come to realize that something happens in your life cannot tie in with whatever you were taught or what you read. Sometimes it can come in a form of doubt or "Gosh, if this can't work out what is going to happen to me?" LA</p> <p>You know, right now, I think that going through the phases of treatment, when you actually find yourself asking (yourself) this question, "Why me at the stage of my life?" You know, who needs to go through this at this stage of this life? Who needs to go through it at all? I find myself asking this question a lot. You know, I wish it wasn't me. I wish that – I wish God sort of explained to me or something where, "Well, I chose you to go through this because you were the strongest in your family and can withstand all of this at this time", you know? I don't know. I wish I had the answers. Trust me, I wish I had the answers. I would like to get some answers but unfortunately, I don't. KS</p>
Spiritual distress is about separation	Separation from god/higher being	<p>To me, I guess, spiritual distress would be getting far away from God (letting myself drift) and not being where I know I'm supposed to be. I'm supposed to be close to him so that I know his will. I think that when this time of distress type of stuff comes is, I know I'm in the wrong type of thing and that I'm not doing what I'm supposed to be doing. So I get, what I could call, distress and have to find my way back. GS</p> <p>Spiritual distress is something that you don't believe in God, right? I feel that they are distressed because they feel that God – they blame God about it so they don't care about God. They don't know what's happening to them. HS</p> <p>You know, when something like this happens and you know, you wake up one morning and this is your life. You say, "Oh my God. What have I done? Look at what has happened. I neglected praying. I neglected asking you for guidance." You know, all of these things. And it has happened to me. So I realize now (and with all of this just happening now) I cannot concentrate the way I would like to, to ask God in any meaningful way to please help me to make that connection once again. You know, it has been hard for me. I wish I could make that connection once again. KS</p> <p>Yeah, something that can make you feel spiritually separated from God. SH</p> <p>Spiritual distress for me is stop believing in God. LMA</p>
	Separation from beliefs	<p>I think of people that are in the darkness, that you don't feel that Jesus is around you...I think you feel that he's not listening to you...you are in a situation where you feel emptiness. You feel afraid...it is spiritual emptiness. RR</p> <p>You know, spiritual distress, I believe to me is a disconnect with your faith (with your religion). You know, with not having that connection... KS</p> <p>...Sometimes you doubt interpretation of scriptures. It can happen, you know? You can doubt interpretation – It would cause some distress in some people. LA</p> <p>Well, I feel that it would be someone who was experiencing – they don't believe in another power or experiencing hopelessness. Yeah, lack of belief is causing them to feel hopeless. PD</p> <p>...The distress I see as an absence of anything positive. CG</p>

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Table 1: Contd...

Themes	Sub-themes	Examples of illustrative quotes from participant interviews
	Separation from fellow believers and practices	<p>I think spiritual distress would be separation...if you are separated, then you've gone through spiritual distress because you – as I said right at the beginning everything is connected - if you see yourself as separate from everything, you will definitely have had spiritual distress...all sorts of fear...you really just can't communicate because you see yourself as separated...IS</p> <p>Spiritual distress is when your heart is really upset (when you can't think, you can't sleep, and you can't do anything). LM</p> <p>Spiritual distress, I feel the people that are lost. They have no goal. They have no path they are walking on. They are on a twisty, windy road with too many forks in it. They decide where I do from here? That's spiritual distress. Like asking yourself, where do I go from here? Yeah. That's to me what spiritual distress is. Not knowing where you are going. Like, am I doing the right thing? Am I going here? Not being able to make up your own mind because you haven't found the answer within yourself yet, you know? They have to find the answer within themselves. SG</p> <p>Well, I guess, yeah, the feeling that existed for a while that no one could help me out of this (my friends, my family, God, the spirit world). I was going down a slide and I was on my way out and so- it was just all gloom and doom...not long, but yes, just in the initial stages when everything was spinning around CG</p> <p>Distress is – distress is, "I don't know what to do. I'm helpless". But for me, spiritual distress really exists. Yes, it feels like a pressure on your heart or whatever on your mind. You don't know what to do but not say it, and you feel helpless. But there can be pressure on your brain. There can be pressure on your heart. LA</p>
Spiritual care is about connecting	Care by a higher being	<p>Spiritual care, uppermost, is to help people to find peace in their lives and in their hearts. Give them strength. Not only something to look forward to, but a belief in God that this is about you and God now, you know? LA</p> <p>Spiritual care is about knowing what really God wants you to do. HS</p> <p>Spiritual care – as I said. We are never abandoned. We are never alone. The Lord always sticks with us...He created us so He cannot leave us alone with the problems. MS</p> <p>My everyday spiritual care is spending time in the Word and coming before the Lord, and all of that. GS</p> <p>I just really believe that the word of God is the thing to share and just – it will just pour over you. Just – yes – and covers you and fills you. Yeah. That, I believe is the most important thing. GS</p>
	Care by a priest/clergy, hospital chaplain	<p>Well, I really appreciated (hospital chaplain) coming in like that. It was a little boost for me just to have somebody to talk to like that...I just felt very comfortable with (name). We established our grounds as who we were and everything like that and what I believed in. GS</p> <p>I know that we all have to die and being a Catholic, you believe that there is life afterward...So as long as the spiritual person talks in a positive way, I'm all for it. Yeah. But if they are going to start talking, you know, saying, "You have to resign yourself". No. I'm sorry. LMA</p> <p>Spiritual care is – our own priest gives us spiritual care. Yesterday a priest came to visit me. That was beautiful. He prayed over me. He prayed for me. We had a prayer. We had good conversation and he left and I felt uplifted. MS</p> <p>Yes, right after my surgery two years ago or so they sent a lady to talk to me. It was nice, you know? But, it was different. She was talking to me about the Lord and stuff about our faith. She was a preacher of the same faith. It was good. MS</p> <p>I mean the priest has been in and giving me communion every Sunday. He drops by and sees me. It's a nice feeling to know that somebody there is wishing you well, you know? PD</p> <p>I think of someone, like a priest, coming talking to me...That's what I think of spiritual care – someone who has - someone who is more knowledgeable than I or as knowledgeable - or prayer. That's what I think of when I think of spiritual care. RR</p>
	Care through Interactions with fellow believers	<p>But yeah – it's having people too, to encourage you and keep you going. GS</p> <p>Spiritual care – I mean, you think about the Jehovah's Witness coming to your door, you know? Things like that. That's what I think about. It's because they are bringing that theological approach to – for you to make that connection once again. KS</p> <p>I admit to people that I have my moments and I need support or if they ask me, I say, "Pray for me". Some of the Christians would come in and take the wrists, tell the scripture and when they come to visit they don't come empty handed. They come with something to help me along the way. This is what scripture says. LA</p> <p>I guess, first of all, the care of the spirits around me. But also, I have several friends who also believe as I do. Their being around me and reminding me of things...they are wonderful. CG</p> <p>I do have a good group of friends that we share a faith. We have a prayer group going. LMA</p> <p>I think the care of your family...Taking care of the family and the family taking care of me and carrying so much, you know? SG</p>
Conversations about spirituality must align with the patient's beliefs	Role of health care professionals	<p>No, I haven't really needed it because I've been doing my own spiritual thing so many years but, you know, I rely on myself for that. LM</p> <p>...Because it's not something people want to talk about anyway (I don't think) because it is very personal. I mean, if my doctor asked me, "Are you feeling/experiencing spiritual distress?" I don't know if whether I would even want to hear that question. I don't know, IS</p> <p>We can make sure (that we are at least going to have/offer) the ability for a person who feels cut off from God. We are going to be a bridge that maybe is more designed towards making that bridge stronger" because that's what it is...a bridge to helping the person not feel so cut off SH</p> <p>Well, I mean, they ask it every day, "How are you feeling?" but do they take the time to stop and listen to what they said. They have to be able to almost read between the lines. LM</p>

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Table 1: Contd...

Themes	Sub-themes	Examples of illustrative quotes from participant interviews
		Yeah, you know, like, "How can I help today?" Those are very simple words, but you know what? It means a lot to somebody who is not feeling well. You know, well they come up and say, "Well, you can't help me with anything". "Well, okay. But I'm here if I can" LM
		But I like it very much - no matter what religion they are, believe me - when they do talk about the Lord, about the faith, these people that come to help us, you know, I really like it. MS
		She (doctor) takes her time...and she listens. She truly listens. She does listen. You can talk all you want...and she truly listens...she has such a gentle manner. RR
	What patients say will help to start conversations about spirituality	...Because they are health professionals...would they ask people about spiritual distress? Okay. You could approach it in this way, but "I am a physician, is there anybody you think of who can help you in this particular time of your life? Do you have anybody you can ask questions, or you know?" You can ask them if they are feeling discouraged and - you could say, well, "How are you feeling now?"...general things. LA
		Oh, spiritual care is just - I guess - the simple term I would use is just respect. It's just - yeah, just simple respect would be the first step...yeah, just - I see respect even though you are in some environment totally different. You've got to respect it, you know, embrace it...any form of separation is not respect. IS
		You know, (ask) "What's happening in your life today that is different than yesterday? You were feeling fine yesterday but today is different. What made that difference?" Sometimes you break it down into pieces because that's how the brain operates. You can't just ask just a broad question. LM
		If it's done in a positive way, I think it's really good. Then it all depends on the person, you know? It all depends on the person, on the beliefs of the person. LMA.
		You know, the best way to approach that, I think it would be - what are their plans for the future? Regardless if they are terminally ill or whatever. I think having something to look forward to, you know? Ask them if they have any plans (anything they want to do or that they are planning to do)?... I don't think I would use any negative words or anything. LMA
		I guess the best way is honesty. So you would just honestly say, "We want to offer you things and these are one of things we offer. Are you interested?" PD
	What patients say will help in having conversations about spirituality	...People come to you and believe that they are helping you and they just bombard you with ideas and bombard you with information. You have to reach a stage when you say to people sometimes, "Can you just listen to me for a little while?" Or "I'm too tired. I can't even understand what you are trying to say to me now or I might react in a way that's not helping me". Know when to stop. LA
		When you are in this distress. I mean, you know it. You feel it. It's very prevalent. It's - okay, how does one deal with that? You know, that's when they need somebody, you know, to go to and just listen to them talk. Even if they say nothing, they've had a chance to binge their ear. LM
		If you respect the reaction of the person, you can - you can reinforce where they are coming from (which is all that really matters). You can't go around telling everyone how they should be. If you respect where they are coming from then they feel it, you know. IS
		...sometimes, if you just let the conversation go, it will take you where you need to go. It is quite an interesting process once you start getting into the spirituality of a person. You know, that person will lead you where you need to go even though they don't know what they are doing...LM

In addition, visits with friends who share the same beliefs provided a sense of spiritual care.

Although participants struggled to find words to talk about spiritual care, common ideas emerged including "respecting you," "people listening to you," "encouraging you," "taking your burden on themselves and helping to bear that burden," "helping people find peace and strength in their lives," and "sharing words of comfort when things are bad." A few individuals spoke about the desirability of focusing on the positive and on things for which they were thankful. They did not want others to talk about things that were negative and would take away their energy or waste it. One participant expressed spiritual care as being able to talk about their spiritual struggle as it was "a bridge to help you feel not cut off."

Theme: Conversations about spiritual needs must align with the patient's beliefs

Participants did not readily identify healthcare professionals as providers of spiritual care. However, when the question was posed, participants expressed viewpoints

about how healthcare professionals ought to engage in conversations with patients about spiritual matters. They spoke about the importance of healthcare professionals understanding when they were upset, listening to their concerns without judgment, and not imposing their own beliefs on the patients. They wanted the healthcare professionals to respect and support the patients' own beliefs.

Participants thought patients ought to have the opportunity to talk about spiritual needs and had many ideas about how a healthcare provider would open such a conversation [Table 2]. For the most part, approaching the topic directly was not seen as helpful. One needed to be gentle, recognizing that talking about spirituality is personal. Once initiated, the conversation would likely take different pathways depending on how the individuals wanted to pursue the conversation. The healthcare professional's role, first and foremost, is to listen, to help the person explore what is upsetting them and to offer what can be done to help the situation. The important aspect is to align the

Table 2: Advice from patients regarding conversations about spiritual needs

Focus of suggestions	Specific suggestions of questions participants thought would be helpful to engage in conversations about spiritual needs
Questions to open a conversation	<p>What would you like to know (about your illness)? Here's what I can tell you, what I know</p> <p>Do you have any worries? What exactly is worrying you?</p> <p>Do you feel scared or feel you do not know what to do?</p> <p>Are you having difficulties in a certain area?</p> <p>Are you finding you are feeling lonely? Alone?</p> <p>Do you feel separated or disconnected?</p> <p>Do you find that life for you is worth living?</p> <p>Do you have friends? Hobbies?</p> <p>How are your negative thoughts impacting your life?</p> <p>How are your positive thoughts impacting your life?</p> <p>What make you happy? What do you think makes the positive happen?</p> <p>What do you find beautiful in nature?</p> <p>How are you feeling (today)?</p> <p>What is different about today? What makes the difference?</p> <p>How can I help you today?</p> <p>How is your day going?</p> <p>What is happening in your world today?</p> <p>Do you have plans for the future? What are you looking forward to? What would you like to do? What are you planning?</p> <p>What kinds of things do you believe in? How are feeling about those beliefs now?</p> <p>Do you need spiritual help? We have things to offer, are you interested?</p> <p>We are here for you</p> <p>Selected: For a patient who has indicated beliefs, staff member could base the conversation on his/her own knowledge of the scriptures: find out how strong the patient's faith is; Did you come to know God? Do you believe in the Lord?</p>
General advice on having the conversation	<p>Be open, honest and gentle? Respect the other and his or her views</p> <p>Do not be afraid of using personal experiences, but do not impose</p> <p>If you ask a question, stop and listen to the answer</p> <p>Do not push your own beliefs</p> <p>Align your conversation with patient's beliefs</p>

conversation with the patient's beliefs and support them in those beliefs.

Discussion

This study was undertaken to explore perspectives about spirituality and spiritual care held by individuals with advanced illness. We hoped to gain insight into their views about the role of health care professionals in providing spiritual care. Although the participants had no difficulty talking about spirituality or what they thought constitutes a spiritual struggle, the notion of spiritual care presented some challenges for them to describe. Furthermore, they did not readily identify healthcare professionals as providers of spiritual care.

For the most part, the study participants included individuals who had a long commitment and participation within a religious community. They were able to state their spiritual beliefs, drawing on their unique understanding and ways of expressing them, and the importance of those beliefs for informing their daily lives. Spiritual beliefs were embedded in their lives and were clearly part of how they defined themselves and their reasons for feeling of hope and comfort. Their faith was evident in practices (e.g., prayer, scripture reading) and influenced their coping with advanced illness. Their faith clearly gave them strength to cope with what was happening to them.^[35,66]

Nonetheless, despite their strong convictions, participants indicated experiencing upset and struggles in facing their diagnosis and advanced illness situation. Being able to express their concerns without being judged, talk with someone who truly understood their perspective, and have their doubts acknowledged were seen as beneficial to them. In some instances, participants had ready access to members of their spiritual community and were able to interact with them, while others did not, especially while in the hospital. Feeling "cut off" or isolated can clearly add to the burden, and suffering patients experience during illness.^[67,68] In addition, some individuals require help in recognizing that healthy expression of doubts can lead to strengthening of one's spiritual beliefs.^[69]

When confronting spiritual doubts or questions, especially while in a healthcare setting, a challenge for patients is knowing where they can turn for assistance. Those who have access to members of their own community may have a readily available resolution to their concerns. They may feel their own religious communities can fulfill their spiritual needs and do not see the hospital staff to have a role in this regard. But for those who do not have easy access to spiritual support or those who are distressed without recognition that the root of their concern may be a spiritual matter, the role of healthcare providers in offering assistance ought to be considered. Currently, there remains a lack of clear role expectations for healthcare providers regarding spiritual care.^[70]

Participants expressed the value of having their concerns acknowledged and having someone who would listen to them without judging. At the same time, they indicated the topic of spirituality was not one to be approached lightly, or in some instances, directly. It is a very personal topic, and individuals have varying degrees of comfort in talking about it. Many of the participants suggested starting the conversation about spiritual concerns with a focus on exploring general topics and allowing the person to reveal what was comfortable for them to discuss. Patients may require a signal or indication

from the healthcare provider that it is acceptable to talk about spiritual topics with them. However, the healthcare provider needs to have the knowledge, skill, and comfort to have these conversations.

The deep exploration of existential subjects in a truly authentic manner demands a knowledgeable and skillful individual.^[71] Most healthcare professionals would not have this expertise nor do they possess a reasonable level of the comfort with the topic.^[72] In addition, such a conversation demands time, patience, and a willingness to be truly present with the individual through difficult personal explorations. The environment of a health care facility, with its focus on time efficiency and task completion, may or may not be conducive to such an exchange. Therefore, the needs of the patients may be best served if the frontline health care provider can recognize when the patient is distressed, isolate whether the issue is of a spiritual nature, and offer to connect the patient with the appropriate expert (i.e., hospital chaplain, patient's own religious leader, another nurse or staff member with similar beliefs) or service.

Implications for practice and research

The results of this study emphasize that the importance of acknowledging that individuals with advanced disease may have concerns that are of a spiritual nature and may be expressed in various ways. It is helpful to patients if frontline healthcare providers can recognize and acknowledge when an individual is struggling with spiritual doubts and orchestrate the necessary connections to resources for assistance. The resources could be an individual within the patient's religious community or one within the healthcare facility. This will require that the health care provider has the requisite knowledge, skill, and comfort level to engage in basic conversations with patients about spirituality. Ensuring staff have the requisite knowledge and comfort in this topic area and finding effective strategies for frontline staff to actually hold these conversations, given the busy nature of the practice environment, are important initiatives for future consideration.

This study focused primarily on individuals with a Christian affiliation and clearly articulated set of beliefs. Future research ought to engage other faith groups as well as non-Believers in similar explorations to uncover how they would approach the topic of spiritual care and the role of health care providers in this matter.

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Conflicts of interest

There are no conflicts of interest.

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