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Toward a clinical model for patient spiritual journeys in supportive and palliative care: Testing a concept of human spirituality and associated recursive states

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Abstract

Objective. In 2015, a Chaplaincy Research Consortium generated a model of human spirituality in the palliative care context to further chaplaincy research. This article investigates the clinical fit of (a) the model's fundamental premise of universal human spirituality and (b) its 4 proposed stage descriptors (*Discovery*, *Dialogue*, *Struggle*, and *Arrival*).

Method. First, we collected qualitative data from an interdisciplinary palliative care focus group. Participants ($n = 5$) shared responses to the statement "the human spirit has essential commonalities across […] groups and […] attributes." Participants also shared vignettes of spiritual care, and 48 vignettes illustrating patients' spiritual journeys were subsequently taken from the transcript of that group. Second, we invited different mixed discipline palliative care professionals ($n = 9$) to individually card sort these vignettes to the model's 4 stage descriptors; we conducted pattern analysis on the results. We then administered a third step, convening six physicians to complete the card sort again, this time allowing designation of cards to one or two of the 4 stage descriptors.

Results. Focus group participants were supportive of the model's all-encompassing definition of spirituality. The concept of "connectedness" was a shared focus for all participants, connectedness and spirituality appearing almost synonymous. Pattern analysis of assigned 48 vignettes to the 4 stages showed stronger consensus around *Discovery* and *Arrival* than *Struggle* and *Dialogue*. Results of the additional card sort suggested *Struggle* and *Dialogue* involve oscillation and are harder to think of as a steady state as distinct from processes associated with *Discovery* or *Arrival*.

Significance of results. "Connectedness" is a productive concept for modeling human spiritual experience near the end of life. As one healthcare professional said: "this connectedness piece is […] what I always look for … " Although further work is needed to understand *struggle* and *dialogue* elements in peoples' spiritual journeys, discovery and *arrival* shared consensus among participants.

Introduction

Human spiritual processes and needs in palliative care have received increasing research attention over the past decade (Breitbart, 2007; Amoah, 2011; Pargament, 2011; Lopez-Sierra and Rodriguez-Sanchez, 2015; Shields et al., 2015; Breitbart et al., 2018). One reason for this is the growing evidence that suggests that spiritual suffering may exacerbate other debilitating symptoms in dying patients, particularly pain (Rippentrop et al., 2005; Boston et al., 2011). Another is practitioner awareness that patients' spiritual and psychological journeys through a terminal illness can be as important as their physical and social experiences (Knight and Emanuel, 2007; Steinhauser et al., 2009; Best et al., 2016; Rego et al., 2018). A primary aim for current research on spirituality in the fields of psychotherapy, healthcare and pastoral care is to articulate the different ways in which practitioners can facilitate patient engagement with existential issues in order to manage suffering and distress (Klemens, 2004; Pargament, 2011). Significant outcomes for palliative care that have emerged from this increased inter-professional and disciplinary alignment have included: quality indicators that measure and document what matters (O'Reilly et al., 2016; Aslakson et al., 2017; Snowden and Telfer, 2017; Flannelly et al., 2018; Fitchett et al., 2020); clinical practice guidelines for psychosocial distress and spiritual care practice (Murillo and Holland, 2004; Bernard, 2017); as well as a number of manualized psychotherapeutic interventions (LeMay and Wilson, 2008; Marchand, 2012; Breitbart et al., 2018; Rodin et al., 2018). Relatedly, many research projects have described endeavors to help patients

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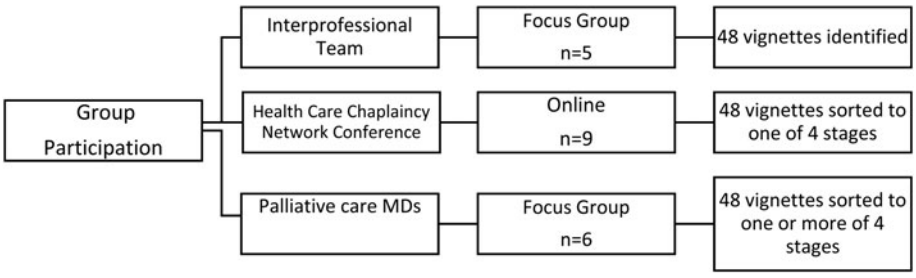

Fig. 1. Flowchart of participant engagement with mixed methods.

through letters, diaries, legacy documents, and other narrative approaches (Cooper, 2011; Emery, 2013; Sumathy, 2019) and attended to the impact that cultural and contextual diversity can have on spirituality and religiosity in supportive and palliative care (Delgado-Guay, 2014; Lopez-Sierra and Rodriguez-Sanchez, 2015; Ahluwalia et al., 2020).

While growth in spiritual care research continues (Damen et al., 2018), healthcare chaplaincy research has felt the need for a common model in which clinical and chaplaincy researchers could locate their hypotheses. In 2015, the Chaplaincy Research Consortium (CRC) published a consensus model for spheres of spiritual experience aligned with domains outlined in models of palliative care and human suffering (Emanuel et al., 2015a). The model built on existing work (Sulmasy, 2002; Puchalski et al., 2009) and defined spirituality as "the aspect of individuals that seeks and perceives significance and experiences connectedness to the sacred." It is notable for its assertions that patients experience spirituality across social, physical, psychological, and spiritual domains and that all of these can interact with the sacred and divine. It draws on a growing body of the literature about processes of adjustment (Knight and Emanuel, 2007; Ching et al., 2009; Kenne Sarenmalm et al., 2009; Ahluwalia et al., 2020). The model posits that individuals are motivated to connect with "what's out there" [external to their selves] and/or "what's in there" [within their selves] in order to achieve peace or well-being, and that they experience 4 stages of adjustment (*Discovery, Dialogue, Struggle*, and *Arrival/Disconnect*) as they engage in that process. Another distinguishing feature of this CRC model is its acknowledgment of the multiple paths a patient may take through these 4 stages in their spiritual experience as they adjust to illness.

Accepting the fundamental importance of spirituality at the end of life (Williams, 2006) and the validity of the idea that existential/spiritual states exist in human psychology, the CRC proposed a definition of spirituality with the explicit aim of facilitating researcher engagement. This definition is "the aspect of individuals that sees and perceives significance and experiences connectedness to the sacred," where the sacred is "feeling connected to or aware of the unknowable, the infinite, immanent or transcendent in a way that creates awe, and seems to be precious, and connected to that which enlivens" (Emanuel et al., 2015a). Although the CRC model aims to facilitate chaplaincy research, this definition does not focus on the work of chaplains alone. Refining all healthcare professionals' understanding of the ways in which patients process spiritual experiences is vital to creating a holistic conceptual framework for research and enhanced inter-professional understanding of patient connectedness at the end of life.

Our study objectives were twofold. The first was to test the responsiveness of various healthcare professionals to the CRC model's definition of spirituality. The second was to test interprofessional assessment of the utility of the CRC model's adjustment process categories (*Discovery*, *Dialogue*, *Struggle*, and *Arrival/Disconnect*) as effective descriptors of stages in the patient spiritual experience.

Methods

Contextual and pilot data were collected through a review of the literature followed by an iterative mixed methods process. The latter is shown in Figure 1. Focus group discussions with interprofessional team members familiar with the patients' spirituality in palliative care settings resulted in vignettes to identify experiences in patient's spiritual journeys. The authors identified a coding approach and a conference call with an advisory group refined the approach. This coding of vignettes was used in an online card sort involving attendees at the annual 2017 Healthcare Chaplaincy Network Conference who were invited to participate. A second card sort was conducted with a focus group of palliative care physicians.

Review of the literature

A literature review using the keywords "spirituality" "supportive" and "palliative care" was undertaken in MEDLINE Web of Science (2001–2019). Excluding articles not written in English, this yielded 59 articles. Content analysis of article keywords showed some recurring themes. These include spirituality defined as a construct that "involves concepts of 'faith' where faith is a belief in a higher transcendent power, but not necessarily identified as God (Breitbart, 2002; Breitbart et al., 2010, 2018; Young et al., 2015)." Patient spirituality as a component of supportive care is frequently understood to be predominantly intrapersonal and conceptualized as a central and internal motivating force that provides a sense of direction in life and/or protection (i.e., providing a sense of meaning/purpose/what matters) (Barnard et al., 2017; D'Souza and Astrow, 2020). Evident in the literature is the conceptualization of spirituality as coping and hopefulness that may be either intrapersonal or interpersonal based on the presence of connection with the sacred (and/or sacred components in life), and the direction that is perceived from the connection (Delgado-Guay, 2018; Prizer et al., 2020). Also important are activities such as music, mind diversion and the creation of healing environments (Delgado-Guay, 2018). In line with this research, spirituality in the context of supportive and palliative care was conceptualized as a motivational process entailing a search for, and connection with, the sacred.

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Table 1. Patient experiences of the sacred

Patient experiences of sacred		Examples provided by focus group participants
Behavior	Talking about mortality, turning toward or away from interaction, turning toward or away from expressions having to do with God, exclusion and inclusion of persons in care settings	A patient is face-to-face with their mortality
		A patient's first instinct is to be spiritual
Activity	Joining a support group, doing manual things like painting, sitting quietly, requesting the presence of another person, turning down offers of support, talking about the illness, talking about values, talking about the day-to-day, talking about the future, religious ritual, setting goals, meditating, telling stories, connecting with family, writing legacy, advocacy, and listening	A patient plans for a life with cancer. She talks to her therapist
		A family requests prayer, Hail Mary and anointment
Feeling	Shock, rage, anger, betrayal, fear, feeling bad, worry, loneliness, abandonment, calmness, peace, suffering, anxiety, terror, understanding and acceptance, tiredness, feeling loved, distress, fear of the unknown	A patient rages against their diagnosis
Thoughts	Desire to know. Examples include posing questions, wanting to change and move life forward, thinking differently, being mindful, finding a Zen place, achieving closure — "now I can go," decision-making, finding meaning, thinking about the future, finding meaning in behavior and activity	A patient finds his Zen place

Focus groups

To explore the concept of patient spirituality in supportive and palliative care, we held two focus groups with five participants. Focus group participants included a psychologist, social worker, a palliative care chaplain, and survivor support group volunteers, one of whom was also a chaplain. All focus group participants were invited to share reactions to the study definition of spirituality and to provide their own observed vignettes of sacred phenomena. Using a deductive approach to content analysis (Elo and Kyngas, 2008), transcripts from the focus were analyzed for consistent themes and phenomena. Process categories and domains were identified using published works (Emanuel et al., 2015b) and our code book incorporated the exemplars of behavioral, emotional, and goal-bound activities modeled in the original published article (Emanuel et al., 2015a). The authors R.J. and L.E. thematically identified and culled 48 vignettes shared during the focus groups as behaviors, feelings, and activities characteristic of patients' spiritual journeys. Coders then assigned these sample vignettes to the 4 stages proposed by the CRC model. To authenticate coding attribution, coders shared initial coding with a single meeting of a mixed stakeholder group, several of whom had authored the original CRC model article.

An early discrepancy discussed and resolved by team members concerned the functionality of two of the 4 stages. Coders found *Struggle* and *Dialogue* to be contested stages with vignette designations to them being difficult. The research team proposed there would be better understanding and consensus if these categories were renamed as *Exploration* and *Working Through*, respectively.

Online card sort

The authors then used OptimalSort to create an online card sorting program. This method has been used specifically in palliative care (Vyjeyanthi et al., 2010) and was chosen to facilitate observation of health professional attribution of vignettes to the CRC's 4 stages. The 48 vignettes were edited by the authors R.J. and L.E. and then presented to participants from the focus groups; the participants assigned each vignette to one of the 4 stages. The card sort was also used following the presentation of the project at the HealthCare Chaplaincy Network 2017 conference in Chicago. A total of nine people attempted this online card sort. Participants included four chaplains, a physician, two researchers, and two others. The results of this activity were further discussed by the participants on a conference call with the research team. Members recommended one final iteration of the card sort with participants being given the option of selecting more than one process category for each card and being allowed to converse about selections. With this addendum, six physicians completed the code sort using the refined categories in pairs.

Results

Our findings are organized to highlight topics that arose during focus group discussion or were flagged by card sort participants in the online comment box. The focus groups and card sorts yielded data about the following themes which we describe below: Spirituality, Connectedness, and the 4 Stages of Recursive Adjustment (*Discovery, Exploration, Working Through*, and *Arrival/Disconnect*).

Spirituality

The CRC model (Emanuel et al., 2015a) asserts that spirituality can be experienced as something in and of itself or as part of the physical, social, and psychological domains. Coders noted that focus group participants concurred with the model's presumption that these domains overlap. As one focus group participant commented: "as a psychologist I struggle to define what is psychological and what is spiritual … a lot of these conversations dovetail." Another commented: "spiritual care … it's going in and whatever they present, whatever they give us, that's the framework and the bedrock — that's the only thing we can work with."

As illustrated in Table 1, content analysis of focus group participants showed the range of behaviors, activities, feelings, and thoughts generated by discussion of the CRC model's definition of spirituality.

Connectedness

Focus group participants were invited to consider the CRC model's precept that it is through the processing of spiritual experience that patients feel "connected to or aware of the unknowable, the infinite, immanent or transcendent in a way that creates awe,

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Table 2. Matching vignettes to the model's 4 stages in recursive processing of spiritual experience

4 stages proposed by CRC model	Matched examples provided by card sort participants
Discovery: The person senses potential to connect with the bigger picture	A patient is face-to-face with their mortality
	A patient's first instinct is to be spiritual
	A patient rages against their diagnosis
Exploration: The person is motivated to engage with the bigger picture	A patient plans for a life with cancer. She talks to her therapist
Working Through: The person oscillates between positive and negative. They look for personal or spiritual resources that help connect to the bigger picture and provide meaning to a new life	—
Arrival/Disconnect: The person feels integrated and at ease. The person's life connects with the bigger picture	A lady knits 16 scarves
	A family requests prayer, Hail Mary and anointment
	A patient finds his Zen place

and seems to be precious, and connected to that which enlivens." While the CRC model "does not specify what it is that connects us all," coders observed that spiritual caregivers who are skilled in observing for phenomena that signify connectedness or disconnectedness have no hesitation in identifying connectedness or providing examples of the phenomena they look for. Content analysis of focus group transcripts showed "feelings, values, and relationships" are the phenomena frequently cited by participating health professionals to characterize their observation of connectedness, with "feeling" being the most frequently cited, and most desired focus for further exploration with patients.

As one participant stated, "I think when a person's first diagnosed, they're vulnerable and they're shaken to their core, because they don't … we never think it's going to happen to us and so everything comes from that — existentially, psychologically, spiritually … Whatever dream they had for themselves or plan that they had envisioned for their life has now been interrupted, so there comes a, just a disconnect and how to reconnect with their story in light of their illness. And what things are valuable to them now … "

Consensus about the 4 stages recursive adjustment

Analysis of the online card sort of 48 vignettes to the 4 revised stages (*Discovery, Exploration, Working Through*, and *Arrival/Disconnect*) showed some level of consensus. Table 2 presents the vignettes that were assigned to one of the 4 stages with an 80% or 100% agreement among participants. Of note are the 2 cards that had a 4 out of 4 match with the stage of *Arrival* ("A patient finds his Zen place" and "A lady knits 16 scarves"). Also of note are the 2 stages with least agreement among card sort participants: *Exploration* and *Working Through*.

On completion of the exercise, participants commented that they felt disadvantaged by not knowing the "contextual nature of ongoing meaning making" or the steps which preceded or followed the example given. One participant wrote: "A lot of spirituality around severe illness and dying is in the moment, so I feel cautious about reading too much into a single sentence synopsis until it shows some relative movement between 2 points (and not that there wouldn't be a return to state A as time goes forward). It's not a simple dance." Another commented: "Spirituality is not discrete. [Need] more context (e.g. progression from A to B vs. a snapshot in time)." In discussion with the broader team, coders observed that this reflected the difficulty they too had experienced when trying to assign vignettes to categories of *Dialogue* and *Struggle*. Despite renaming both stages as *Exploration* and *Working Through* it appeared these were still a challenge for participants.

In keeping with the literature that shows professional training is a key factor in providing an interpretative framework for spiritual states and outcomes (Ledbetter, 2001; Hall et al., 2012, 2013; Shields et al., 2015), participants mentioned their familiarity and professional comfort with states that were similarly theorized by the model's stages. One clinical psychologist commented that the definitions given for the 4 distinct stages overlapped with those they used to facilitate Acceptance Commitment Therapy (Low et al., 2016).

To address the emerging hypothesis that the *Exploration* and *Working Through* stages were rarely seen as isolated stages but more as precursors to other stages, we offered an additional group of professions, two palliative care physician pairs, the option of selecting two placements for any of the cards they struggled to assign to a single adjustment stage. Physician participants took the option for 25% of the 48 cards, commenting that they had observed patients to be in more than one place at a time. Cards placed under the header *Exploration* or *Working Through* were paired six times with each other and cards placed under *Working Through* and *Arrival* were placed five times with each other. *Discovery* and *Arrival*, on the other hand, were only paired once. One possible explanation for this is that *Exploration* and *Working Through* are states of mind more frequently characterized by extra activity, moving between states, than *Arrival* or *Discovery*.

Discussion

A long-term goal of the CRC model is to help researchers in patient spirituality in supportive and palliative care situate their hypotheses in a flexible and multidisciplinary model of the human spiritual experience. The goal of this exploratory study was to shed light on the clinical utility of key aspects of the model. Our study contributes to the literature by showing consensus among health professionals providing supportive and palliative care (including a psychologist, social worker, palliative care chaplain, and palliative care physicians) that an experience of

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"connectedness" characterizes palliative care patients' diverse experiences of spirituality despite the fact that, as one participant commented: "specifics are different." Participants in our study also affirmed that spiritual experiences exist within physical, psychological, and social occurrences and not only in purely spiritual occurrences. Participants could readily identify the stages from the CRC model of *Discovery* and *Arrival* but were less able to identify stages of *Exploration* and *Working Through* until able to pair those stages with other stages. This suggests that there may be multiple paths through these stages and that some of these stages may be experienced simultaneously.

The limitations to our study are ones that are shared with other studies of spirituality in palliative care (e.g., Bonsignore et al., 2001; Bech, 2004) and include the use of category-based approached and the use of "single item experiences." Category-based approaches are necessarily limited in their capacity to discover novel and unexpected relations between the individual and their states of being because the categories used to summarize experience are typically developed rationally and are, thus, constrained by prior theory and researchers' intuitions (Shields et al., 2015). As we have described, 2 of our 4 stage descriptors needed further exploration. In addition, our multi-method qualitative approach utilized single experience vignettes as proxies for processes, an increasingly common practice in healthcare contexts (Johnson et al., 2016) but one which downplays contextual nuance.

Despite these limitations, we believe that this study provides evidence which advances the capacity of healthcare professional to utilize research to advance spiritual and palliative care. Recommendations to continue to improve the CRC model's utility include further development of methods to capture the necessarily subjective and unique, yet fundamental and potentially generalizable spiritual processes of patients. Statistical modeling of processes identified in multiple patient stories, for example, could facilitate understanding of how individuals typically move from stage to stage and identify the care skills that are more or less effective at each stage. Methods developed by narrative identity researchers to ensure research is inclusive of narrative and personal storytelling may also prove fruitful (Adler, 2010, 2012) by allowing for more diverse descriptions of these stages and their relationship to each other. Further work will help to elucidate how these stages can be elicited from patients, how they can be discussed with colleagues and whether there are therapeutic implications that vary by stage.

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Conflict of interest. The authors have no conflicts of interest.

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