

Experiences and Expressions of Spirituality At the End of Life in the Intensive Care Unit

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Running head: Spirituality in the ICU

Key words: Spirituality, End-of-life, Death, Intensive Care Unit, Palliative Care

Word count, excluding abstract & references: 3500

Word count, abstract: 250

Contributions:

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Abstract

Background: The austere setting of the intensive care unit (ICU) can suppress expressions of spirituality.

Objective: To describe how family members and clinicians experience and express spirituality during the dying process.

Setting: 21 bed medical-surgical ICU

Methods: Reflecting the care of 70 dying patients, we conducted 208 semi-structured qualitative interviews with 76 family members and 150 clinicians participating in the 3 Wishes Project. Interviews were recorded and transcribed verbatim. Data were analyzed by 3 investigators using qualitative interpretive description.

Results: Participants characterize dying as a spiritual event. Spirituality is an integral part of the life narrative of the patient before, during, and after death. Experiences and expressions of spirituality for patients, families and clinicians during end-of-life care in the ICU are supported by eliciting and implementing wishes in several ways. Eliciting wishes stimulates conversations for people of diverse spiritual orientations to respond to death in personally meaningful ways that facilitate continuity and closure, and ease emotional trauma. Soliciting wishes identifies positive aspirations, which provide comfort in the face of death. The act of soliciting wishes brings clinician humanity to the fore. Wishing makes individual spiritual preferences and practices more accessible. Wishes may be grounded in

spiritual goals such as peace, comfort, connections and tributes; they may seek a spiritually-enhanced environment, or represent specific spiritual interventions.

Conclusions: Family members and clinicians consider spirituality an important dimension of end-of-life care. The 3 Wishes Project invites and supports the expression of myriad forms of spirituality during the dying process in the ICU.

Introduction

Medicine, in its fullest expression, may be a spiritual discipline [1]. Spirituality refers to the way individuals seek and express meaning and purpose, and how they experience connectedness to the moment, self, others, nature, and the significant or sacred [2]. The World Health Organization identifies spirituality as a core dimension of health [3], which may sustain people at times of distress. Critical illness raises common existential questions about meaning, purpose, relationships and destiny. However, the ICU is not a setting where these questions are typically addressed.

An ATS policy statement cites the identification of spiritual needs as a core competency for critical care practitioners [4]. Spiritual support is one of 7 end-of-life care quality domains in the ICU [5]. Families of ICU patients often want their spiritual values incorporated into discussions; while meeting this need is associated with family satisfaction [6,7] this may be uncommonly realized [8].

With the globalization of society, the world grows increasingly spiritually and culturally diverse [9]. The objective of this study was to describe how family members and clinicians experience and express spirituality during the dying process in the ICU in the context of the 3 Wishes Project, the overall aim of which is to bring peace to the final days of a patient's life, and to ease the dying process [10].

Methods

Patients and families in the ICU were eligible to participate if there was a decision to withdraw advanced life support or after the physician estimated probability of death in the ICU to be $\geq 95\%$ [Figure 1]. After verbal consent, bedside clinicians and the project team elicited and implemented wishes from the patient, families and clinicians to dignify the patients' death, honor and celebrate a patient's life, and foster humanism in practice.

Following written informed consent, we conducted semi-structured interviews with family members of enrolled patients and their clinicians. Interviews investigated participants' experiences of spirituality during the project. We recorded and transcribed interviews verbatim, using NVivo® for data management.

Initially 5 investigators (2 with qualitative research experience and 3 spiritual care investigators) independently reviewed coding reports on data responding to questions about spirituality from 13 family interviews and 80 clinician interviews, then created a preliminary coding list by consensus. All transcripts of 76 family members and 150 clinicians were re-read by 2 investigators, one of whom coded all transcripts. The final descriptive analysis [11] was performed by 3 qualitative investigators who read coding reports and organized the codes for the reporting framework. Interviews iterated with analysis and proceeded through redundancy for key themes.

Some results herein were reported in abstract form [12].

Results

Reflecting care for 70 patients [Table 1], we interviewed 76 family members [Table 2] and 150 clinicians [Table 3] (208 interviews - 71 staff, fellow, or resident physicians; 46 nurses, 9 chaplains and 24 allied health professionals).

Participants experience dying as a spiritual event, to be integrated within the life narrative of the dying person. The 3 Wishes Project expresses spirituality in 2 ways - first, by soliciting wishes - asking the patient, family, or clinicians what they wish for, and second, by fulfilling wishes - addressing spiritual needs through wish implementation [Figure 2]. Among 317 implemented wishes, 4 spirituality categories were: comfort and peace; connections and reconnections; personal tributes; and spiritual rituals and practices [Table 4].

Dying as a Spiritual Event, Integrated Within a Life Narrative

Participants widely acknowledge spirituality's importance in end-of-life care. Many spoke of dying with words of spiritual transition or journey, with clinicians as witnesses and companions. *"I'm always very privileged to share in someone's last breath. I think that, for a family to allow you to share that...it's a very personal thing."* (Nurse) Clinicians and family members aim to understand what this journey meant and asked of them along the way. *"I think everybody - even if they don't describe themselves*

as religious or spiritual - they do seek meaning...when someone's at risk of dying, or when death is looming." (Physician). Dying makes many daily concerns suddenly irrelevant. Fundamentals came sharply into focus, *"I think, because for me, spirituality is the core of who that person is. It's how they make meaning in life and what they value... death seems a sharpened focus on all those things."* (Chaplain) The bedside transformed into a spiritual place: *"In the room when someone's dying, there's...there's a lot of sacred stuff going on...there's a lot of spiritual stuff going on..."* (Brother).

In this "sacred space" some people are compelled to fulfil religious duties. For others, dying evokes unfamiliar thoughts about the meaning of life and death, need for closure, or how to honor the dying. Eliciting wishes provides a vehicle for their questions:

"Now, as you see the end of your life approaching, what are you thinking about? What does that mean for you? What are you struggling with? What are you scared about? What do you hope for? All of that. I can't see getting at that without allowing space and time and permission for clinicians to... ask very simple questions about who this person is before them." (Nurse)

A dying person's story reaches into the past, through to the present, and beyond the death, e.g.,: *"...and they had mentioned that, you know, once their father passes away, he could be reunited with their mother in heaven."* (Resident), and *"...celebrat[ing] this transition from this life to the next."* (Chaplain) Concern for future

narratives included planning the disposition of the body, understanding the spirit's destiny, and anticipating bereavement for loved ones.

“[My Uncle] wasn't religious. He didn't, you know, go to church. When we were filling out the paperwork for his surgery here and it says 'religion', he said to me, 'No thanks.' ... But when he was in the ICU...and I was having to make decisions regarding life support and all kinds of stuff, the hospital chaplain was there. One of the wishes was that she would be at the funeral. She was there for us.... She didn't know him through life but she knew him through the stories and through the 3 Wishes and coming and talking to me every day.” (Niece)

Soliciting and fulfilling wishes helps to create healing moments in the story of each dying person. Clinicians identify these acts as spiritual in quality, highlighting two mechanisms - easing emotional trauma and achieving closure. Through engaging spiritual questions, many grieving people move towards accepting death as a part of life: *“They ask questions about why, and ask about the meaning of life and they ask questions about closure and things undone, things unsaid, life after death for some people, regret and hope...It calls all of that forth...” (Physician)*

Spiritual Experiences in Wish Solicitation

Participants characterize spirituality as "what matters most" at the end-of-life. Because a wish is a positive aspiration, requesting wishes generates hope and affirmation when people suffer despair and despondence. Asking about wishes “sets a stage” for spirituality. Soliciting wishes acknowledges imminent death, shifting focus from "what

is the matter with the patient?" to "what matters to the patient?" [13]: *"The medical side - it becomes less relevant and something like the 3 Wishes program helps you reflect and makes you think more about the spiritual side of things and the patient's wishes."*

(Resident) Clinicians *"...[just] see the person as a person...that's where the spirituality piece comes in."* (Nurse) A physician more graphically described how soliciting wishes reclaimed personhood: *"So you're in this situation...with gear and gadgets and wires and tubes in a very impersonal environment and [3 Wishes] brings dignity and respect back into the environment. Or, it ensures that it...that it's got a place in the room, because I think often...often, it might not."* (Physician)

The act of asking, in itself, invites people to voice their spiritual values, goals, and concerns: *"It's just simply by asking the question... To me, that just does it right there..."*

(Chaplain) Soliciting wishes makes some spiritual practices more accessible. Many cultures involve spiritual practices for death; repressing these can exacerbate suffering. For the religiously-affiliated, wishes clarify compulsory faith-based observances. One family requested bedside recital of Quran verses, turning the patient toward the east, and direct transferral of the body before burial to the mosque. A Muslim fellow noted that *"...granting these wishes that are very relevant to the Muslim faith will have a great influence in the short and long term ...for the family members..."* (Fellow)

Many persons without an active faith community desire spiritual connection at this time, *"When you're in and around death and dying, all of a sudden these beliefs that they didn't have for - like 30 years - are back, because they're so scared."* (Nurse) Wishing

helps to locate that missing support. One family declined a chaplain's visit when offered as usual, but later requested her presence as one of their wishes. Another dying person's mother recounted:

“People that have that social network in the church and have a priest or a minister or somebody that they can go to for help in these times may turn to that for support.... We didn't have that. We don't have that. So this [3 Wishes] was kind of like that, right? Kind of like a way of helping us to cope and get through it and do that...” (Mother)

Religious or not, many people feel bewildered by the dying experience and yearn for someone to help make sense of it all:

“Cause at that time, when things like that happen, you know, we think of other things. We think of God and we think of heaven and stuff. I think we should have someone who may be able to answer those questions for us. Tough questions that they may be.” (Brother)

For people with strong non-religious identity (e.g., religion is nonsense"), or personal beliefs (e.g., characterizing a father's spirituality as being "nature"), soliciting wishes invites expressions of spirituality. A resident explained, *“When you offer things that are non-denominational, that have some of the elements of spirituality but...are a bit more secular... I think it's just easier for families to get involved with the program, and approach it.”* (Resident).

Initiating wish solicitation, clinicians step outside the conventional professional role with new-found intention for deeper human connection: *“It has to be a human encounter. Like, it can’t be ...technical...it can’t be a checklist of questions that I ask you...”* (Nurse) This human-to-human stance can be deeply moving. Some identify this act as profoundly spiritual. The humility and compassion of the gesture, and the egalitarian exchange acknowledging shared humanity and vulnerability, brings solace. A resident described:

“It’s a ‘want to do more’. It’s a want to try to reach out to something that’s beyond just something that could be seen...it’s a form of love... agape love or it’s kind of a very unconditional... you’re just kind of exuding a type of...a love into... this person and the family and I think that’s the sense of spirituality that I get and can bring forth... asking for the wishes.” (Resident)

An observer of the clinician-family interaction described being moved:

“And then [the physician] moved into ...a conversation with them about the 3 Wishes and I was like, ‘Whoa. Wow.’ I was quite breath-taken and in fact... for most of the time that I was in the room...I put my hand up to my chest, up to my heart... , I was really quite breath-taken... The humanity of [the physician] ...”
(Chaplain)

Some clinicians view spirituality as "not their business", or only territory for clinicians with spiritual affinities. *“[Spirituality has] almost been trained out of me ... I’m in the very early stages of my career still and you see kind of like, a divide between people [who]*

retained that ... spiritual side in their practice; and then the ones that are almost a little too clinical and a little too rational.” (Resident)

“I mean, we ask all these very private questions about patients. Like, we know their eating habits, their sexual habits, their drug habits and all this information and we have no problems with asking it but then when...when it comes to faith and spirituality, I think there’s this barrier for us. We feel uncomfortable asking them questions...” (Resident)

Clinicians feeling ill-equipped often perceive spiritual care as outside the scope of their practice [14]:

“Sometimes when you have difficult discussions about end-of-life and the families are very religious, for me, it can be hard because I don’t know enough about their beliefs...Like, when someone does pass away... what does that mean for them? So when families say stuff like, ‘But God wouldn’t want this,’ I don’t really know... how am I supposed to explain what God wants because I’m not someone who knows, if that makes sense.” (Resident)

Soliciting wishes offers a pragmatic way for clinicians to minimize discomfort, discerning needs, then access spiritual resources. A chaplain explained:

“[The project] ... gives an opportunity to talk about spiritually significant parts of a patient’s experience without lading clinicians with a whole scope of practice that is maybe intimidating... I often hear from other clinicians that they just don’t have time to do all that. So that this gives them a way into that without having to feel responsible for the whole... scope of their spiritual care.” (Chaplain)

By contrast, other clinicians draw on their own spirituality for strength to respond to grief they encounter daily. Fulfilling wishes gives clinicians vehicles for compassion - a central value across many belief systems. Prayer helps others: *“I did really, honestly pray that they would find some peace. So for me, I definitely found, just personally, a bit of solace in my own spirituality.”* (Nurse) “Being present” is another commonly-valued spiritual practice:

“...you know, we were there and, and just sitting with them and talking to them ... I feel kind of awkward because I’m not so sure what the difference is in, between, spirituality and, and just being there and being connected with the person.”

(Nurse)

Regardless of differences, clinicians' own spirituality helps to recognize spiritual needs in others:

“The patient had been very spiritual throughout her life - not necessarily following a specific religion but just very spiritual in nature ...I feel as though her belief in whatever it was... was important to me because I respected the fact that my religion was quite important to me, so I could understand the basis of her spirituality.”

(Respiratory Therapist)

Clinicians self-identifying as spiritual or religious consider it important not to influence others, *“What I would call my faith tradition gives me an attentiveness to spiritual matters and spiritual care. So I value it and I’m highly attuned to it. I think it’s just how I’m programmed to be. I struggle with language so I’ve always struggled, as a nurse...because I’m so aware of not imposing my beliefs on anyone.”* (Nurse)

Soliciting wishes helps families become aware of their needs during the stress and exhaustion of a fatal illness. Soliciting wishes can comfort and heal those grieving. One daughter described it as *"lifting the gloom"*. A chaplain explained *"...there was sort of a lightness brought into the dark."* (Chaplain)

Finally, soliciting wishes addresses tremendous spiritual diversity. *"In my own practice, it's all about trying to understand what does spirituality mean for this person...this patient or this family that's in front of me? And then just honour that, in whatever way."* (Nurse) Wishes educate clinicians about varied spiritual approaches to death and bereavement: *"I think spirituality is different for everyone and every family, and they all will express it in their 3 wishes in many different ways... we might not think it's spirituality, but to them, it is, and you just have to go with it and respect what they want to do."* (Nurse)

Spiritual Dimensions of the Wishes Themselves

Some wishes for soft lighting, silence, or soothing sounds nurture spiritual feelings [15], e.g.: *"I think singing was very spiritual for them; I think that was a big part of their spirituality. The music was always on when I was there, for two days, always."* (Nurse) Some wishes are religious (e.g., inviting a patient's own rabbi) or assisting with rituals (e.g., smudging ceremony). Wishes post-mortem can cultivate the patient's spiritual mission. A wish for one man was donation to a conservation area: *"...Is there something that's important to Mr. C.?' and it was like, 'Oh, nature.' That's his*

spirituality... it really supported...the family engaging a lot of the spirit that they had seen within their father.” (Chaplain)

Wishes often concern values common across belief systems, such as peace and comfort. Where there is strife and despair, wishes cultivate peace. Some wishes comfort the dying – e.g., the familiarity of watching the sports channel around the clock, “[*sports is*] what gave him joy in life and it was nice that that’s the way he parted as well as that he had what gave him comfort” (Medical Student). The bereaved seemed comforted through wishes, as in the death of a young person:

“...it seemed tragic, and the response that the family had to his impending death was really tragic, too, because they were so desperate and so angry. And I really saw a change in their demeanor; I saw a change in them fighting to give up on him to just, just accepting that he might die and letting go. And I think that all happened when we introduced 3 Wishes. There was sort of a peace about them.”

(Nurse)

Many wishes are individualized keepsakes in the form of a locket of hair, a final family photograph during a life celebration in the patient's room, or a commemorative framed word cloud for reminiscing:

“One of the things your [3 Wishes] program had done was to provide very personalized prayer cards...very personalized to her, with prayers and her name...What I was expecting to be a very cold [experience] ended up to be almost oddly beautiful. We all sat around and held hands and that little paper that you

made, I still keep...I keep it with her other possessions and it's like any of her keepsakes;...it's just as valuable to me as any of the others." (Son)

A common wish is for reconciliation. Wishes can help to restore family communication and to dissipate tensions. A requested ICU wedding, for example, cleared the air: *"I mentioned the family arguing... everything that needed to be said, I believe was looked after. And in the end, the day before the wedding...there was a sense of calm."* (Nurse) Longing for forgiveness motivated a mother's wish for reconnecting with her estranged son. One woman's gracious wish on behalf of her ex-husband, was to tell his first wife years after their divorce, how proud he was of the children they had raised.

Discussion

Across belief systems, death is experienced as a spiritual event. Families strive to integrate death into a patient's narrative. By soliciting and honoring wishes, clinicians can acknowledge and sustain the patient's life story, helping with closure for loved ones. Soliciting wishes envisions hopeful measures that can be taken during the dying process, and brings clinicians' humanity to the fore. Clinicians endorse expression of common spiritual practices such as compassion [16,17] and presencing [18] - even posthumously [19] - in their roles. For clinicians without a spiritual orientation, soliciting wishes offers strategies to broach an unfamiliar subject [20]. While a clinician's own spirituality may help to recognize spiritual needs in others, refraining from imposing personal beliefs is a stance underscored by the patient-centred ethos of the 3 Wishes Project.

Common wishes pursue spiritual goals such as peace, comfort and love. Reconnection is an especially powerful, poignant wish of persons separated by distance or discord. Frequent secular wishes are for a spiritually-enhanced environment. Others are for religious rituals. Soliciting wishes helps families revive lapsed spiritual supports, while respecting preferences of those avowedly non-religious or holding private views.

Limitations of this study include no quantitative metrics of dying processes, bereavement, or post-traumatic stress [21]. Although many clinicians may offer basic spiritual support, we acknowledge that trained professionals [22] are crucial to assist with spiritual distress [3], yet consultation is often deferred to end-of-life.

The spiritual needs of dying patients and families appear to be poorly recognized and addressed in a venue where physiology, technology, and efficiency are emphasized [23,24]. However, the ICU is potentially a powerful setting for reflecting on experiences and expressions of spirituality. As aligned with the European Association of Palliative Care Taskforce [25], we developed an interdisciplinary strategy to ask about, and address, the human spirit in this setting.

We offer an approach to explore and respond to spiritual diversity [26,27]. Actions may speak louder than words in this context. Soliciting and realizing wishes fosters spiritual care by prompting myriad interventions that are directly or indirectly interpreted as spiritual [28]. Many people, whether self-reportedly spiritual, religious, both, or neither - regardless of remote or recent affinity - call forth a spiritual response when bearing witness to death. The 3 Wishes Project helps to realize the spectrum and impact of spirituality for those dying, living, and working in the ICU.

Acknowledgements

We thank all the patients, families and clinicians who participated in the 3 Wishes Project. We are grateful for the nursing, physician, respiratory therapy, chaplain and social work staff in the St. Joseph's Healthcare Hamilton ICU for their commitment to humanism at the end of life. We thank Lois Saunders, Nicole Zytaruk, Shelley Anderson-White, Neala Hoad, and many nurses and residents for helping with the realization of several wishes. We appreciate the quantitative analysis by Diane Heels-Ansdell, graphics expertise of John Rose, and the transcription assistance by Diana Clancy and Laurel Grainger. We thank Drs Daren Heyland, Graeme Rocker, Wes Ely, and Randy Curtis for encouragement with this project, and anonymous peer-reviewers for their excellent suggestions. This study was peer-review funded by Covenant Health and the Hamilton Academy of Health Sciences, and benefited from donations from the Canadian Intensive Care Foundation, Canadian Tire Foundation as well as several physicians, families and friends who donated to the 3 Wishes Project to help other dying patients and grieving families. This work was motivated by the inspiring work of the Sisters of St. Joseph in Hamilton.

Legends

Figure 1: Study Schema

Figure 2: This figure illustrates the integration of death into the patient's life narrative through the practice of soliciting and fulfilling wishes

Table 1: Characteristics of Patients

Table 2: Characteristics of Families

Table 3: Characteristics of Clinicians

Table 4: Examples of Realized Wishes Supporting Spirituality

Table 1: Patient Characteristics

Baseline Characteristics of 70 Patients	
Age, years, mean (SD)	67.2 (14.5)
Female, n (%)	33 (47.1)
Race, n (%)	
White	63 (90.0)
Non-white	7 (10.0)
APACHE II score, mean (SD)	29.3 (9.2)
ICU admitting diagnosis, n (%)	
Cardiovascular/vascular	25 (35.7)
Respiratory	22 (31.4)
Gastrointestinal	8 (11.4)
Neurologic	4 (5.7)
Sepsis	9 (12.9)
Renal	2 (2.9)
Spiritual or Religious Affiliation, n (%)	
Agnostic	12 (17.1)
Anglican	5 (7.1)
Baptist	4 (5.7)
Catholic	25 (35.7)
Christian	1 (1.4)
Lutheran	1 (1.4)
Muslim	2 (2.9)
Presbyterian	1 (1.4)
Protestant	3 (4.3)
United	1 (1.4)
Unknown	6 (8.6)
None	9 (12.9)
Hospital Course	
Advanced life supports administered at any time in ICU, n (%)	
Mechanical ventilation	69 (98.6)
Inotropes	46 (65.7)
Dialysis	24 (34.3)
Advanced life supports withdrawn just before death, n (%)	
Mechanical ventilation	43 (61.4)
Inotropes	11 (15.7)
Dialysis	4 (5.7)
Spiritual Care consult in ICU, n (%)	51 (72.9)
Palliative Care consult in ICU, n (%)	19 (27.1)
Hospital admission to ICU admission, median (IQR), total range, days	0 (0-8)
ICU admission to death, median (IQR), days	6.5 (4-17)
Hospital admission to death, median (IQR), days	9 (4-29)
ICU admission to 3 Wishes Project enrolment, median (IQR), days	5 (2-11)
3 Wishes Project enrolment to death, median (IQR), days	1 (0-2)

Legend for Table 1: APACHE = Acute Physiology and Chronic Health Evaluation; SD = standard deviation; ICU = intensive care unit; IQR = interquartile range

Table 2: Family Member Characteristics

N=64 Interviews with 76 Family Members	
Days from patient death to interview, median (IQR)	116 (45-210.5)
Interview type, n (%)	
Face-to-face	36 (56.3)
Email	1 (1.6)
Phone	27 (42.2)
N=76 Family Members Interviewed	
Relationship to patient, n (%)	
Spouse	15 (19.7)
Partner	3 (3.9)
Friend	7 (9.2)
Sibling	10 (13.2)
Parent	7 (9.2)
Child	27 (35.5)
Other	7 (9.2)
Age, years, mean (SD)	55.7 (12.1)
Sex, n (%)	
Female	46 (60.5)
Male	30 (39.5)
Spiritual or Religious Affiliation, n (%)	
Agnostic	10 (13.2)
Anglican	2 (2.6)
Baptist	3 (3.9)
Catholic	19 (25.0)
Christian	6 (7.9)
Muslim	2 (2.6)
Protestant	1 (1.3)
Spiritual	2 (2.6)
United	1 (1.3)
None	5 (6.6)
Unknown	25 (32.9)

Legend for Table 2: IQR = interquartile range; SD = standard deviation

Table 3: Clinician Characteristics

N=150 Clinicians	
Days from patient death to interview, median (IQR)*	13 (5-25)
Interview type, n (%)	
Face-to-face	148 (98.7)
Email	1 (0.7)
Phone	1 (0.7)
Profession, n (%)	
Physician	71 (47.3)
Nurse	46 (30.7)
Spiritual Care Clinician	9 (6.0)
3 Wishes Staff	4 (2.7)
Physiotherapist	2 (1.3)
Dietician	1 (0.7)
Social Worker	1 (0.7)
Respiratory Therapist	6 (4.0)
Other	10 (6.7)
Years working in critical care, median (IQR)	3 (0.4-12)
Age, mean (SD)	37.0 (12.1)
Sex, n (%)	
Female	91 (60.7)
Male	59 (39.3)
Spiritual or Religious Affiliation, n (%)	
Agnostic	16 (10.7)
Anglican	8 (5.3)
Baptist	2 (1.3)
Catholic	35 (23.3)
Christian	27 (18.0)
Jewish	3 (2.0)
Muslim	15 (10.0)
Presbyterian	1 (0.7)
Protestant	1 (0.7)
Spiritual	12 (8.0)
United	3 (2.0)
Unknown	1 (0.7)
None Indicated	12 (8.0)
Other	14 (9.3)

Legend for Table 3:

IQR = interquartile range; SD = standard deviation

Table 4: Categories and Examples of Realized Wishes Experienced and Expressed as Spiritual By Family Members or Clinicians

Comfort and Peace

- personal items at the bedside (e.g., healing stones, rosary)
- decorating patient's room for special occasions (e.g., Easter, Valentine's Day)
- trip outside to hospital garden
- moment of silence after failed resuscitation of homeless person

Connections and Reconnections

- retelling family travel tales
- father to make amends with his son
- patient to see longstanding colleague one last time
- final photograph of family and friends taken around patient's deathbed

Personal Tributes

- creating keepsake for remembrance (e.g., locket of husband's hair for his wife)
- gift of ICU team for the family (e.g., Father's Day cake post-mortem)
- life lessons from patient (e.g., partner sharing secrets of her long marriage before she died)
- family gift to staff (e.g., wife's needlepoint given by her husband to bedside nurse)

Spiritual Rituals and Practices

- bedside chanting by family
- staff offering of smudge stick to patient's sons
- bedside prayers or sacraments (e.g., last rights)
- spiritual care for wife after her husband died

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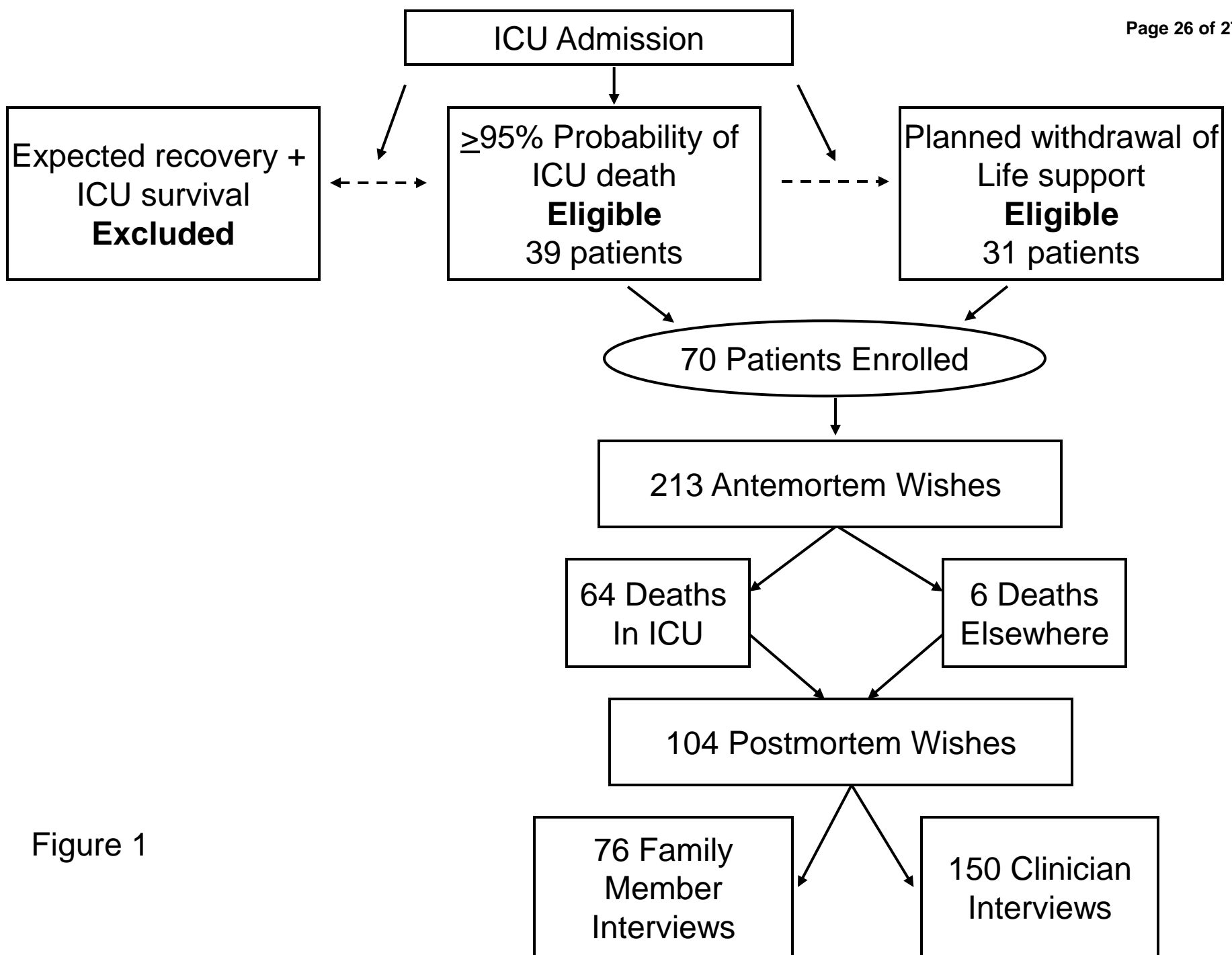


Figure 1

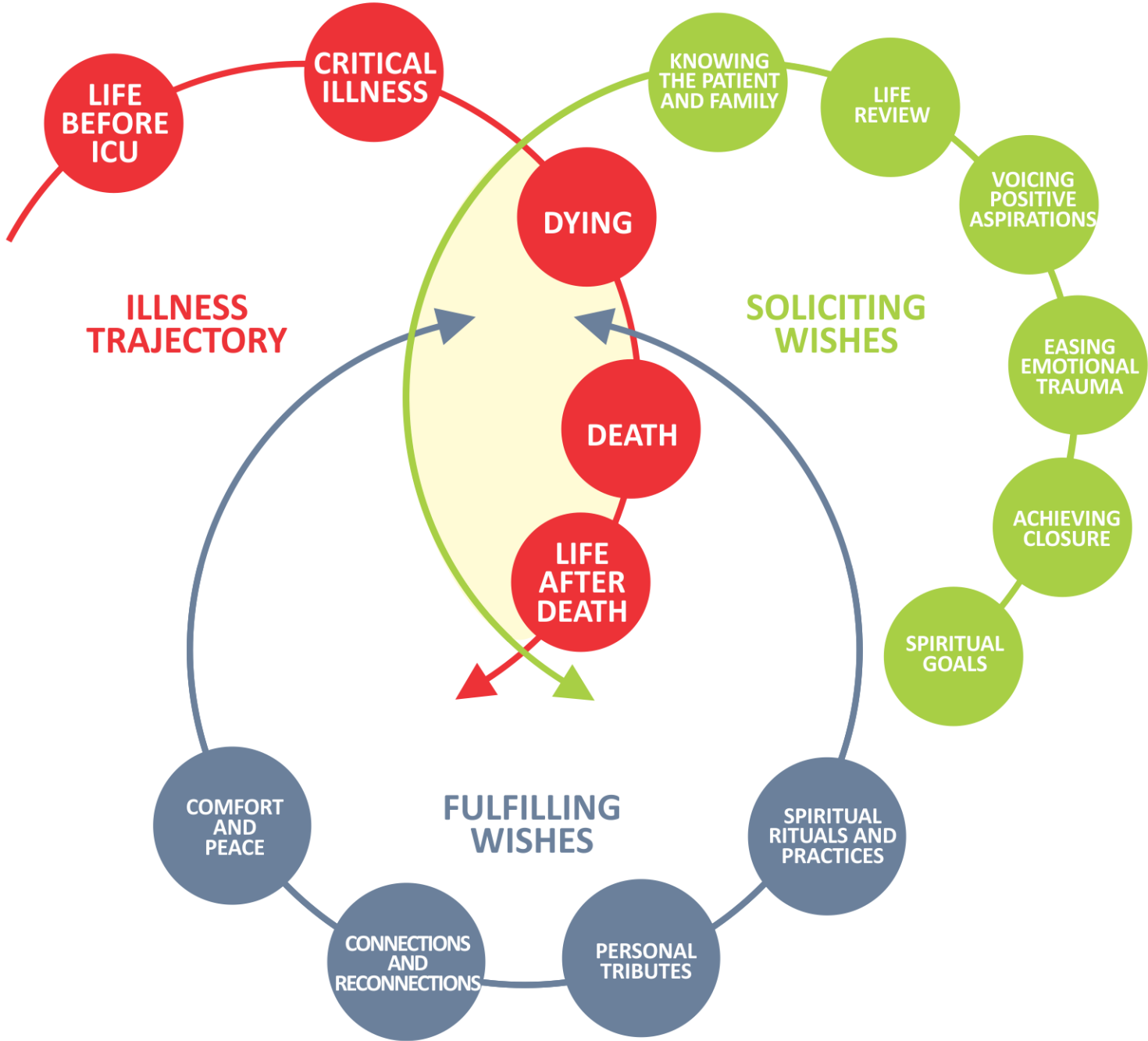


Figure 2