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Patients' and caregivers' contested perspectives on spiritual care for those affected by advanced illnesses: a qualitative descriptive study

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Abstract

Context: Spiritual care refers to practices and rituals addressing spiritual/religious concerns.

It supports coping with loss and finding hope, meaning, and peace. Although integral to palliative care, its implementation is challenging.

Objective: To understand an Australian cohort of patients' and caregivers' perspectives about experiencing and optimizing spiritual care in the context of advanced illness.

Methods: Patients and caregivers of patients with ≤ 12 month prognosis were recruited from a broader spiritual study via criterion sampling and agreed to opt-in interviews. Participants from an Australian, metropolitan health service received a spiritual care definition and were interviewed. Transcripts were analysed using qualitative description.

Results: Thirty patients (17 male; mean 70-years) and 10 caregivers (6 male; mean 58.9-years) participated. Twenty-seven identified as Christian and 10 had no religion. Participants described multifaceted and contested beliefs about spirituality. Many queried the tangibility of spirituality but all valued respectful staff who affirmed personhood, that is, each individual's worth, especially when care exceeded expectations. They also resonated with positive organizational and environmental tones that improved holistic wellbeing.

Participants stressed the importance of the hospital's welcoming context and skilled care, which comforted and reassured.

Conclusion: While many patients and caregivers did not resonate with the term, "spiritual care", all described how the hospital's hospitality could affirm their values and strengthen coping. The phrase "spiritual care and hospitality" may optimally articulate and guide care in similar, pluralist inpatient palliative care contexts, recognising that such care encompasses an interplay of generalist and specialist pastoral care staff, and organizational and environmental qualities.

Keywords: palliative care, spirituality, spiritual care, patients, caregivers, hospitality

Introduction

Spiritual care is an essential component of compassionate and dignified care of patients and families grappling with advanced illnesses.^{1,2} Spiritual care can be described as secular practices and religious rituals which attend to spiritual suffering³ and help restore hope, resilience, and sense of peace and transcendence.^{4,5} Attending to spiritual or religious needs may ameliorate suffering and console many as illness impacts and the afflicted seek life's meaning and purpose.⁷⁻⁹

Patients and informal caregivers report wide-ranging spiritual concerns spanning existential, psychological, religious, and social domains,¹⁰ and seek support from specialist and non-specialist health-workers.¹¹⁻¹⁴ Up to 85% of cancer patients reported at least one spiritual concern² and such concerns have been associated with poorer quality of life.¹² Nonetheless, spiritual support improves coping⁸, care satisfaction,¹⁵ quality of life,^{15,16} and hospice utilisation.¹⁷

In an international focus group study, patients and caregivers reported diverse spiritual care definitions, from religious support to any care beyond physical needs; human connection with staff was considered essential.¹⁰ Further, common spiritual care that North American patients and caregivers received from clergy, healthcare professionals, and family/friends included help with coping with the illness, and with relationships with loved ones or God.⁵ Patients also considered spiritual care to include nurses' offers of prayers, physician inquiries about faith and medical decision-making, and affirmation of beliefs by general staff.¹⁸ A Canadian study comparing patients and healthcare professionals' definitions of spirituality and views on spiritual care reported concordance and discordance. Both groups agreed that spiritual care encompassed active listening, whole person care, family care, and recognition of religion's role. Patients aligned spiritual care with all empathic care, however, health-workers considered that spiritual care was a chaplain's role.

Further, while patients' spirituality included "immediate small things in life", health-workers' spirituality focussed on finding meaning and seeking purpose.¹⁹

Importance of hospital-based spiritual support was especially evident in a study reporting that patients approaching end-of-life who were well supported by religious communities and receiving additional spiritual care from medical teams experienced higher rates of hospice use (adjusted odds ratio [AOR], 2.37; 95% CI, 1.03-5.44, p=0.04), fewer aggressive interventions (AOR, 0.23; 95% CI, 0.06-0.79, p=0.02), and fewer intensive care unit deaths (AOR, 0.19; 95% CI, 0.05-0.80, p=0.02).¹⁷ Hospital-based spiritual care, however, is inadequately offered,^{10,11,18,20,21} with models sparsely described^{4,22} and integrated,²³ particularly for caregivers.¹ This is likely hindered by widely varying health-worker,^{24,25,26} patient, and caregiver^{10,27} definitions of spirituality and spiritual care, and, arguably, spirituality's over-inclusive meaning.²⁸

Despite ongoing spiritual distress experienced by patients and families²⁹⁻³¹ and recognition of spiritual care as a core domain within international guidelines,³²⁻³⁴ implementation of spiritual care across palliative care has been challenging.^{10,19,35} The multifaceted nature of spirituality definitions also renders it a difficult area to research.³⁶ This study aims to contribute an Australian perspective to the evolving international literature by exploring a cohort of patient and caregiver perspectives about experiencing and optimizing spiritual care in the context of advanced illness.

Methods

Design

A qualitative descriptive approach was used, incorporating grounded theory techniques of inductive, comparative, and cyclic analysis.^{37,38} The design reflects the constructivist belief

that perceived reality is constructed from historical, social, and individual contexts.³⁷ The “consolidated criteria for reporting qualitative research checklist” guided study reporting.³⁸

Setting and Participants

Participants were recruited between January 2017 to July 2018 from Cabrini Health, a private, not-for-profit healthcare organization providing acute, subacute, aged, and specialist palliative care services in Melbourne, Australia. Participants were drawn from those recruited by palliative care clinicians for a questionnaire study examining spirituality in palliative care. These participants could opt-into a follow-up interview. Patients with advanced illness, with clinician determined prognoses of ≤ 12 -months, and caregivers of such patients were eligible. Patient and caregivers were unpaired, invited separately, English-speaking, and aged ≥ 18 years. Cabrini Health’s Human Research and Ethics Committee approved the study (2nd November, 2016; Number: 07-12-09-16) and participants provided verbal consent.

Data Collection

Participants completed semi-structured, audio-recorded phone, or face-to-face interviews in inpatients’ rooms in an oncology ward or palliative care unit with CO (first author), where they were provided with a spiritual care definition as defined in the hospital’s pastoral care brochure. Interview questions inquired about experiences at Cabrini which helped them to connect with what they considered sacred or important to their wellbeing, how the hospital could improve this experience, and recommendations for how general and pastoral care staff could improve the wellbeing of all patients (if patient participant) or caregivers (if caregiver participant). The interview framework, including the spiritual care definition, is in Table 1 along with questions used for both patients and caregivers. Although the hospital definition stated that spiritual care focuses on helping people to be connected “to what is sacred to you” (Table 1), we used the term, “sacred or important to you”, in case participants did not resonate with the religious connotation of “sacred”. In Australia, 32% do not identify with a

religion³⁹ and spirituality can refer to how individuals experience their connectedness to the sacred or “significant”.³² Sampling was criterion⁴²: willing participants were interviewed in the time available for data collection, up to a maximum of 30 patients and 30 caregivers.

Data Analysis

Patients’ and caregivers’ transcribed interviews were initially analysed separately. Analysis involved coding (researcher created labels for textual segments), category development (labels representing comparable code groups), and thematic development (labels representing comparable category and code groups). Initial analysis was conducted by CO with qualitative data management software assistance.⁴³ To achieve rigour, an inter-rater reliability strategy was used:⁴⁴ four authors (JB, WD, DG, AM) examined the data and analyses and discussed and reworked the findings with CO until agreement was reached. Meta-ethnography, a method for synthesizing qualitative studies,⁴⁵ was used to synthesize the patient and caregiver analyses, that is, themes and categories from both analyses were compared and contrasted to generate higher-order themes and categories. CO conducted this synthesis, which was then read by all inter-raters. All inter-raters agreed that the synthesized findings satisfactorily represented the data that they had analysed. The patient and caregiver data analysis procedure is graphically illustrated in Figure 1. Additionally, participants’ spiritual care recommendations were deductively (directly) extracted from interview transcripts and presented in a Figure, and descriptive statistics were calculated for numerical demographic and background data.

Results

After 106 patients and 82 caregivers completed the aforementioned spirituality and palliative care questionnaire, 41 patients and 17 caregivers had opted-in to participate. Subsequently, 30 patients and 10 caregivers completed interviews (Figure 1). Mean patient and caregiver

interview lengths were 25.5 minutes and 35.1 minutes respectively. The majority of participants were male (57.5%), married (65.0%), and Australian born (80.0%). Patients' and caregivers' mean ages were 70.0-years and 58.9 years respectively. Most identified as Christian (67.5%) and caregivers predominantly cared for people with advanced cancer (Table 2). Three major themes emerged. Further illustration of data analysis is in Table 3.

Theme A. Contested, Multidimensional Beliefs about Spiritual Care.

Spirituality as a Contested Concept. After listening to the hospital's definition of spiritual care, many participants described mixed interpretations and attitudes towards both terms, "spirituality" and "spiritual care". These are described here and illustrated in Figure 2.

Spirituality and religion could be "one and the same" (patient 6) or distinctive:

I find the word spiritual hard to really pin down as to what that actually means, you know. Because people are using it now in a definition that means more than just being religious. (caregiver 7)

Others discussed spirituality's broad application, with a patient commenting that "spirituality (is) without borders" and "for everybody would be different" (patient 12). One criticized the term's usage because:

I'm an atheist so I had trouble with the term spirituality because I think it's often hijacked to implicate that atheism or rationalism can't have values which I think is completely wrong. (patient 28)

The term, "spiritual care", widely resonated where assistance was provided with: coping with illness and its effects, conversations to achieve peace and calm, ameliorating fear of death, and reflection on meaning. Others queried need for the term. One stated, "It is not based on spirituality but just the fact that the staff there are always kind" (caregiver 3).

Despite the interviewer's regular use of the terms "spiritual(ity)" and "sacred", only 19 patients and 9 caregivers mentioned "spiritual(ity)", mostly to inform definitions (n=10) and recommendations (n=15). Only four articulated "sacred". One queried, "In terms of connecting with the sacred would it not be better and more efficacious to go to the parish church?" (caregiver 4)

Although the term, "spiritual care", did not resonate with all participants, when they were given the definition of spiritual care (Table 1) all related to concepts within the definition, that is, care which connected people to what was important to them, and brought them a feeling of overall health and wellbeing: All esteemed care which supported families, respected religious views, and/or improved life quality. A patient emphasized staff making his life as:

pleasant as possible. So that you can want to live life to live rather than live life to die. ...when I have days that are pain free, I think of planting my calla bulbs in the garden, and having more grandkids and living life as much as I can, as long as I can.
(patient 10)

Mixed Views about Clinicians Inquiring about Spiritual WellBeing. Participants further disagreed on whether spiritual care could be offered by all staff, only spiritual people, or pastoral practitioners. Many were unconcerned about clinicians inquiring about their spiritual wellbeing:

They might say maybe, "Could you say a prayer with me or hold my hand or"
anyone can do that, whether it be a doctor, a nurse, and it might just be that source of solace for that person's comfort at that precise time when they're coping with the realities. (patient 11)

It's simple just to ask, "Is there anything you would like to have done or anybody you would like to see?" or you know, during your time here other than the family and all

the rest of it, you know, from the spiritual point of view or whatever it is To a lot of people that means a lot. (caregiver 5)

Participants also considered the question relevant to discern faith based care issues (Table 3, A2). Some were, however, opposed, explaining it was too personal, embarrassing, and culturally sensitive, or beyond clinicians' remit. Comments included: "I don't need the doctor to ask me whether I believe in God" (patient 29), and "Professional health care person has got a job to do. They really can't compromise based on cultural or spiritual beliefs" (caregiver 2).

Theme B. Respectful Staff Care Affirms Holistic Personhood.

Valued General Staff Qualities and Behaviours can help People to Feel like Individuals. Staff qualities of thoughtfulness, respect, honesty, and expertise were identified as important for enabling participants' overall sense of spiritual wellbeing, or general wellbeing. Participants especially valued "relationship-oriented" (patient 24) care that exceeded expectations and enabled them to feel like individuals. This included staff initiated personal conversations and efforts to return to provide assistance even when busy elsewhere. A patient said a nurse noticed her in a shopping centre, and that for: "Twenty minutes she sat down and, 'Oh M_____, how are you going?' And talked to me and it wasn't like it was a chore" (patient 9). Likewise a caregiver valued:

Staff offering me a cuppa when they come and give dad his cup of tea. ... so I don't have to go down to the cafeteria" (caregiver 3).

Unsolicited care was interpreted as staff empathy. (Table 3, B1)

Several patients valued affirmation of their cultural and faith-based expressions: “If people came in while I was praying, they’d go away and come back later. They respected my time and space” (patient 5). Another acknowledged how staff assisted a patient’s family celebrate Shabbat,

There’s a Jewish lady in the room here, ... their Friday night, I think (nurse) said it’s called Shabbat, they held here, and they had a room for that, with the families, and family from America. I thought, I wish you’d invite me in. (patient 21)

Participants sought frank discussions about illness trajectories to prepare for what was ahead:

The transparency of the doctors telling me that ... he’s not necessarily progressing extremely well and that eventually the dose he’s taking will stop working and then the next steps (caregiver 10)

A volunteer who shared personal grief also inspired a caregiver to consider that, “some positive can come out of” (caregiver 2) the experience of loss.

Pastoral Care Practitioners can Relieve Burden and Affirm Faith. Patients who had received pastoral (including religious leader) care mostly spoke of their caring attitude, acceptance, assurance, and affirmation of faith. A patient’s doubt lifted as pastoral care “guid(ed) me through prayer, offering the Eucharist, and just listening” (patient 4). Two patients, however, found such visits intrusive (Table 3, B2). Many valued receiving faith-based care, notably prayer cards, end-of-life sacraments and rituals, and pocket crucifixes to “focus your thoughts or your emotions on” (patient 19). A caregiver described drawing strength and comfort from a pastoral care led service which included the words “soul” and “next life” after his father died, because “Someone with spiritual beliefs is typically confident about the next life”

(caregiver 2). Another was comforted that his father had received such care (Table 3, Theme B2).

Patients often welcomed pastoral care offers for conversation even when refusing as it indicated the hospital cared. In some cases, patients' pastoral needs were already met at their church or elsewhere: "I was the personal assistant to the parish priest for many years, ... so I don't see that personally, there's a need there from pastoral care, in my situation" (patient 11).

Theme C. Cabrini's Organizational and Environmental Ethos Affects Individuals' Holistic Wellbeing.

Organizational Tone Affects Inpatients' and Caregivers' Holistic Wellbeing. Participants described features of Cabrini's organization (policies and services) which conveyed that what was important to them was respected. A caregiver was reassured that the hospital's anti-euthanasia stance reflected his values; as it generated confidence in care received by his wife in the inpatient palliative care unit, and a sense of holistic wellbeing as he felt supported caring for his wife in this setting. Elsewhere, recently passed euthanasia legislation made him:

feel like you're a drain on hospital resources. This kind of legal decision ... will just further entrench some of the attitudes that I already experience. (caregiver 7)

Another, however, feared inadequate pain relief because some "morality doesn't like the idea of deliberate termination of life" (caregiver 4). Other important organizational qualities included ward quiet times, chapel service announcements, availability of mental health professionals, bereavement follow-up, massage, mindfulness, and art therapy, which

helped a patient go to his “spiritual side ... (and) what’s important” (patient 9). The “general caring” of music therapy and scented aromas could also add to the “overwhelming positive experience” (caregiver 2). Consistency in staff was welcome to mitigate repetition of clinical stories and to promote relationship-building. A caregiver also liked not being asked about his wife’s advance care plan every admission, as occurred elsewhere because it was perceived as, “they’ve written us off” (caregiver 7).

Environmental Tone Affects Inpatients and Caregivers’ Holistic Wellbeing. Participants also described Cabrini’s environmental features which conveyed that what was important to them was respected. The inpatient palliative care unit was described as a homelike cosy, safe haven, which made one feel welcomed and “confiden(t) that there is another life ahead” (caregiver 2). Valued features included: large family gathering spaces where children could play, natural light, cleanliness, outdoor areas, wall hangings, and flowers. Many appreciated the chapels, including broadcast of services to patients’ televisions to support remote engagement in prayer, and religious icons which reflected how the hospital aligned with beliefs. A patient recalled visiting the welcoming chapel after 50 years of religious disconnection,

There’s a little chapel in the place, means there is a sign there for you to say, you want some peace for a little while, come sit here. And I did that the other day purely because it was so long since I’d sat in a chapel ... It took me back to that and that pleasant feeling of calm and peace. ... I was surprised myself that it was so easy to slip back in to that. (patient 24)

Overall, while participants diverged in views about spirituality and regularly did not resonate with the term, “spiritual care”, all described how the health service’s welcoming

hospitality strengthened their resilience and affirmed personhood, that is, conveyed their value as individuals. This care was experienced within an interplay of specialist pastoral and generalist staff care, and organizational and environmental tones.

Figure 3 presents participants' recommendations for how the health service may extend how patients and caregivers can connect with that considered spiritual. This includes recommendations by participants who could not relate to the "spiritual care" term, but could relate to part of the spiritual care definition, which focussed on what was important to people. Recommendations were focussed on staff empathy training and secular and multi-faith based support materials, services, policies, and architectural features.

Discussion

This study delineates how patients and caregivers can have divergent and contested views about the scope of spirituality and related care, affirming and illuminating diverse spiritual care definitions previously reported in palliative care literature.^{10,19,26} All participants also described general and pastoral staff qualities demonstrated towards themselves or others which optimized their holistic wellbeing. Such valued human interactions, alongside the health service's tone of care, reinforced the dignity of each person. Even when participants could not resonate with the term, "spiritual care", they appreciated how the health service offered *hospitality*, a term also linked to palliative care through medieval hospice shelters for weary travellers.⁴⁶

"Spirituality" has evolved from a faith-based concept to a collective term representing transcendence of "ordinariness", and a widely shared definition of spiritual care remains necessary to develop research-based interventions.³⁶ Patient and caregiver acceptance of a shared definition may, however, be problematic. The integral domain of spiritual care in

palliative care did not resonate with many participants in this study, which questions the view that “illness is a spiritual event” for everyone affected by a terminal illness.^{47,48} Our findings suggest that illness can be a spiritual, religious, and/or values-based event, depending on individuals’ interpretations. While engaging with spiritual concerns is a fundamental aspect for some people facing advanced illnesses,^{2,10,49,50} others do not report spiritual needs.²⁴ Furthermore, spiritual care’s connotation of attaining meaning or religion may be inappropriate for those with pluralistic worldviews: a singular focus of attaining meaning through one’s spirituality may distract health-workers from enabling patients’ spiritual exploration through everyday “small things”.^{19,28} It may also alienate those struggling to find meaning in inexorable suffering.⁵¹

We suggest that alongside spiritual care, attention to the timeless virtue of hospitality is needed to guide person-centred care. Hospitality studies focus on the nature of relations between host communities and guests.⁵² Hospitality is characterized by many of the staff and organizational qualities valued by participants in this study: friendliness, kindness, concern for another’s comfort rather than pure acts of duty, going beyond what is generally expected, communicating “something of oneself”, and striving to be available to all needing care.^{53,54} Each person is regarded as a unique, unrepeatable individual rather than “problem” to be solved.⁵⁵ The key to hospitality is attentiveness: to divest from self-preoccupation and to demonstrate a genuine interest in the other.⁵⁵ Unconditional hospitality is impossible,⁵⁶ therefore provision of genuine hospitality to patients and caregivers requires a generous but prudent presence to prevent burnout. Offering spiritual care and/or hospitality is an inclusive palliative care approach, which acknowledges, respects, and addresses pluralist values evident among individuals and communities receiving care.

We suggest further examination of how staff can affirm patients’ and caregivers’ personhood and holistic wellbeing through offering a sustainable prudent presence, which

includes an open authenticity beyond the scope of duty but avoids compassion fatigue.

Examination of feasible and fiscally realistic organizational and environmental tones, which complement spiritual care and hospitality embedded in human relationships is also warranted.

Strengths and Weaknesses/Limitations

The qualitative interview findings offer important insights unhindered by constraints possible in some other methods. For example, closed-ended question tools may reveal information important to researchers but not necessarily participants,⁵⁷ and focus group participants may ventriloquize others' views or avoid disclosing beliefs considered unacceptable.⁵⁸ However, the findings are also from a single, faith-based, not-for-profit and privately funded Australian organization located in a major metropolitan city. It included a high proportion of Australian born participants (although Aboriginal and Torres Strait Islander people were not represented) who readily agreed to an opt-in interview when completing a survey for another study. The questions used in the interview framework also specifically focussed on care experiences in one Australian health service and a specific definition of spiritual care was used, whereas, definitions of spiritual care can vary internationally.^{10,19,36} Also, views from people with same affiliations, including "no religion", are also not always shared.^{59,60} Therefore, thematic findings were not saturated and caution is needed when considering them in relation to regional Australian and international contexts. Nonetheless, we suggest that the findings are logically generalizable⁶¹ to other comparable, pluralist palliative care settings, including in USA where 24% identified themselves as a not a spiritual person⁶² and in Western Europe where 53% stated that neither spirituality nor religion is important.⁶³

Conclusion

Spiritual care was a contested concept among patients and caregivers affected by advanced illnesses. While participants broadly agreed that respectful, honest, expert staff, and welcoming organizational and environmental tones optimized holistic wellbeing, this was construed as either spiritual care or solely as “care”. Although some queried the intangible spiritual concept, all could relate to part of the definition of spiritual care provided and report on care that connected them with what they considered important. We suggest that illness is a values-based event, with person-centred palliative care involving a systemic interplay of human relationship, organizational, and environmental qualities, and that the phrase, “spiritual care and hospitality” can optimally articulate and guide care in pluralist palliative care settings.

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Table 1
Semi-structured Interview Framework for Patient and Caregiver Participants

Researcher Preamble: In this interview I will be describing the Cabrini definition of spiritual care and asking you some questions related to the definition. The first part of the statement is this: At Cabrini Health, spiritual care focuses on helping people to be connected with what is sacred or important to them, and what brings people an overall feeling of health and feeling of wellbeing.¹

1. In the context of your experience at Cabrini, what helps you to feel connected with what is sacred or important to you? Examples?
2. What reduces your feeling that what is sacred or important to you is respected at Cabrini? Examples?
3. How could Cabrini improve your connection to what is sacred or important for you?

Researcher Statement: Cabrini Health encourages all staff to offer generalist spiritual care, that is, assist patients' and families' overall sense of wellbeing and feeling that what is sacred or important to them is respected.^{1,2}

5. How can Cabrini general staff improve the wellbeing of patients from all multicultural and religious backgrounds?
6. Should doctors and nurses ask about patients'/caregivers³ spiritual and religious wellbeing?

Researcher statement: At Cabrini, pastoral services staff offer specialist spiritual care, that is, focus on assisting those particularly challenged by questions about purpose, meaning, hope, faith, and loss. This includes through, for example, offering companionship or counselling, meditation, prayer/reflection, organization of sacraments and visits from representations of faith traditions, and blessing rituals¹

7. What are your recommendations to pastoral service staff, for improving the wellbeing of patients/caregivers³ from all multicultural and religious backgrounds?

¹ Cabrini's definition of spiritual care informed by the Cabrini Health Pastoral Services Brochure, available online: <https://www.cabrini.com.au/assets/Uploads/PASTORAL-CARE-6PG-DL.pdf>

² Informed by Health Service Mission Statement, available online at: <https://www.cabrini.com.au/about-us/our-mission-and-values/>

³ The term "patients" was used for patient interviews, and "caregivers" for caregiver interviews.

Table 2
Patient and Caregiver Backgrounds and Clinical Characteristics

	Patients (n=30)	Caregivers (n=10)
Age (years)	70.0 (SD 11.8; 46-93)	58.9 (SD 14.4; 41-82)
Sex (female)	13 (43.3)	4 (40)
Relationship Status		
Married/Defacto	22 (73.3)	4 (40.0)
Widowed	2 (6.6)	1 (10.0)
Single	4 (13.4)	3 (30.0)
Divorced	2 (6.7)	2 (20.0)
Country of Birth		
Australia	23 (76.7)	9 (90.0)
United Kingdom	4 (13.3)	0 (0.0)
Other ^a	3 (10.0)	1 (10.0)
Diagnosis ^b		
Advanced cancer	30 (100.0)	7 (70.0)
Other \geq	0 (0.0)	3 (30.0)
Caregiver Relationship to Patient		
Partner		4 (40.0)
Offspring		4 (40.0)
Granddaughter		1 (10.0)
Sibling		1 (10.0)
Length of Main Illness ^b		
< 6 months	7 (23.3)	1 (10.0)
6 – 12 months	6 (20.0)	2 (20.0)
1- 5 years	13 (43.3)	4 (40.0)
\geq 5 years	4 (20.0)	3 (30.0)
Religious Affiliation		
Christian	21 (70.0)	6 (60.0)
Buddhist/Christian	0 (0.0)	1 (10.0)
Jewish	2 (6.7)	0 (0.0)
Non-religious	7 (23.3)	3 (30.0)

Data presented as number (%) or mean (SD); minimum- maximum

^a Germany (2), Egypt, USA

^b Caregiver data is for patient cared for

Table 3

Participants' Illustrative Quotes Informing High Order Categories and Themes

Themes & Categories	Patient Illustrations (patient ID)	Caregiver Illustrations (caregiver ID)
Theme A. Contested, multi-dimensional beliefs about spiritual care		
A1. Spirituality as a contested concept	I've probably got a thing about you know, people sort of preaching at you ... to me it's (spirituality's) going to be, just being at peace with myself knowing that I've done my best all my life, to do the right thing. (3)	Religion in some ways, ... I get something out of it but it's like for lots of people it's just a nothing because of everything that's happened in their lives. I think pastoral care's more about spiritualism and offering something else in that space. (9)
A2. Mixed views about clinicians inquiring about spiritual wellbeing	... the Jehovah's witness people who need some urgent treatment to do with blood ... It may pay them (doctors) to find out in case they have a lawyer on their back. (30)	Care is the word ... pastoral and spiritual (are) very fuzzy words. (3) Their medical background, invaluable, and their ideas on medical things is extremely important and I don't think they should be involved in spiritual matters. (1)
Theme B. Respectful staff care affirms holistic personhood		
B1. Valued general staff qualities and behaviours can help people to feel like individuals	I've got a stoma and I leaked. And I mean, they (nurses) were just wonderful (during outpatient visit) ... I've got poop everywhere, ... how embarrassing for me, and they just helped me, cleaned me up. ... they could have just left me there, to wipe myself, but no ... it just made me feel more comfortable, like a person. (17)	As we got to the door, (6 said) "Can I just have a minute?" and they'd (doctors) say, "Yes that's fine", you know, "What do you want to know or what can I do for you?", so it was good to have that 'cause sometimes you don't want to upset the patient with what you want to ask. (6)
B2. Pastoral care practitioners usually relieve burden and affirm faith	It's really nice that the pastoral care ... come and just have a talk to you. It's good to hear what you've gotta say, or you can talk about things that are happening to you and ... they can just give you some reassurance through, through, through your faith. Reassure your faith, that what you believe in is right. (2) There were a couple of pastoral care workers ... I felt it was intrusive of them to ask: "Oh what are you in here for?" or "what have you had done?" (16)	Dad had a lot more conversations with (pastoral carer) than certainly what I had with him. And that, having someone there when perhaps I wasn't, was also comforting so, you know, that was important to me. ... even though we're not overly religious or spiritual on a day to day basis, obviously when death is at the door you do have a different perspective and you want to believe in a higher being and that the loved one is going to be going off to a better place. And obviously (pastoral care) was there to confirm that effectively. (10)
C. Theme C. Cabrini's organizational and environmental ethos affect individuals' holistic wellbeing		
C1. Organizational tone affects inpatients' and caregivers' holistic wellbeing	I mean I know there's a lot of Jewish people there for example, because you know, it's got a Jewish menu. (3) (Art therapy) It centred me because I can go back in and say: What do I want to draw? What do I want to do? ... I don't know if it's part of the spirituality or not, but I think that, if you draw that in, and whatever makes you happy in that part of it, could be part of it. (9)	I found that follow up phone call ¹ quite good in the sense that, you know, you go through, it's quite a stressful thing that you go through with the hospital, and when, when you walk out the door after the patient has passed there's sort of, that's the end and it's quite nice to, I found it quite nice that there was that follow up phone call. (10)
C2. Environmental tone affects inpatients' and caregivers' holistic wellbeing	It's light and airy, and so it's not a dark sombre sad place... it's that brightness as well. It's, it's a really beautiful chapel. ... (and) with just having some of the areas you know, in and around the garden even to sit, be quiet with your own thoughts. (8)	When the kids were sitting in the lounge room and so on you never get that sense. It's clearly relaxed. It's very peaceful. The design of it is very homely. The staff almost like friends, neighbours. I never got the sense that I was in a hospital. (2)

Optimizing spiritual care

¹Standard bereavement follow-up phone call from pastoral care

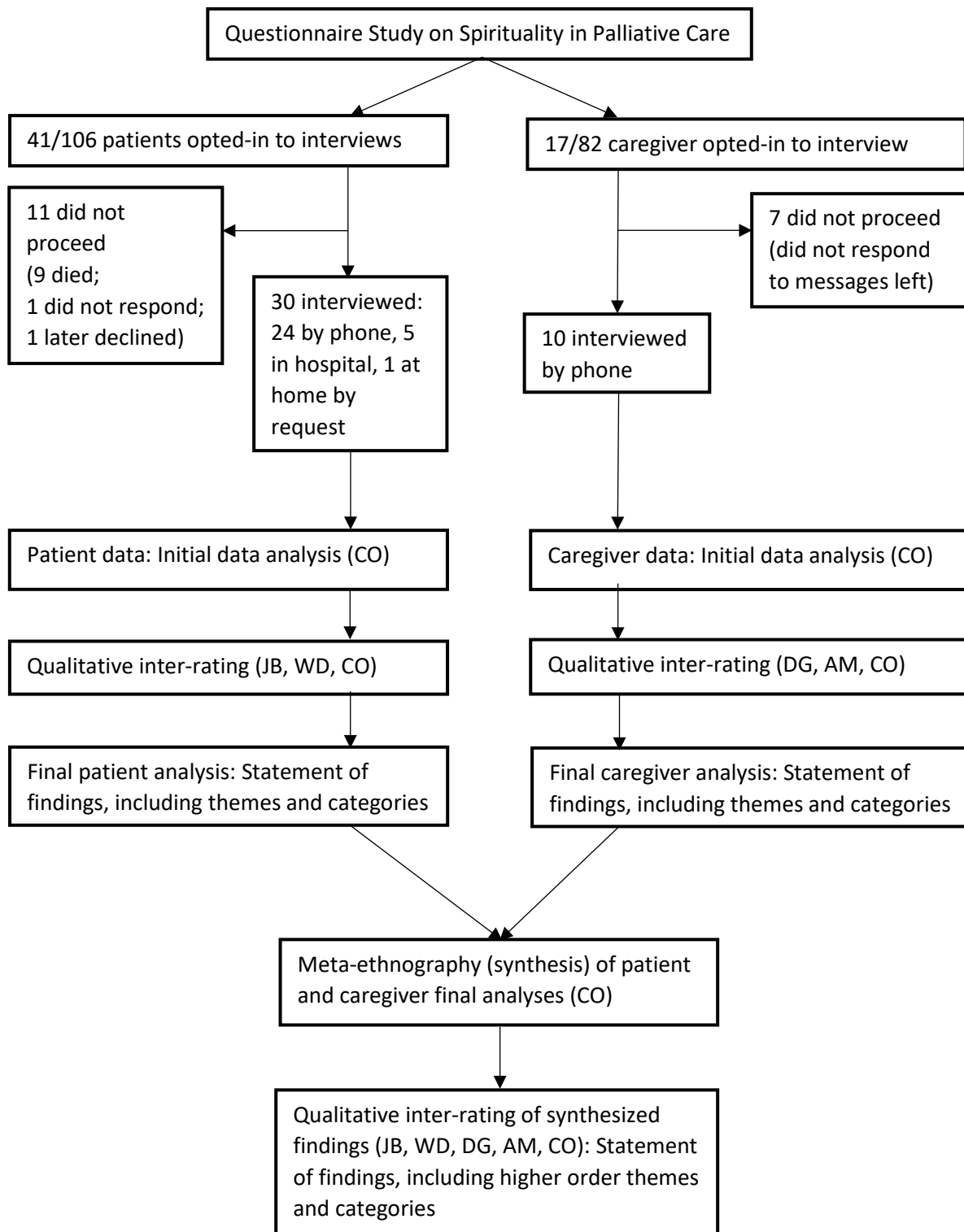


Fig. 1. Patient and caregiver data analysis procedure.

Optimizing spiritual care

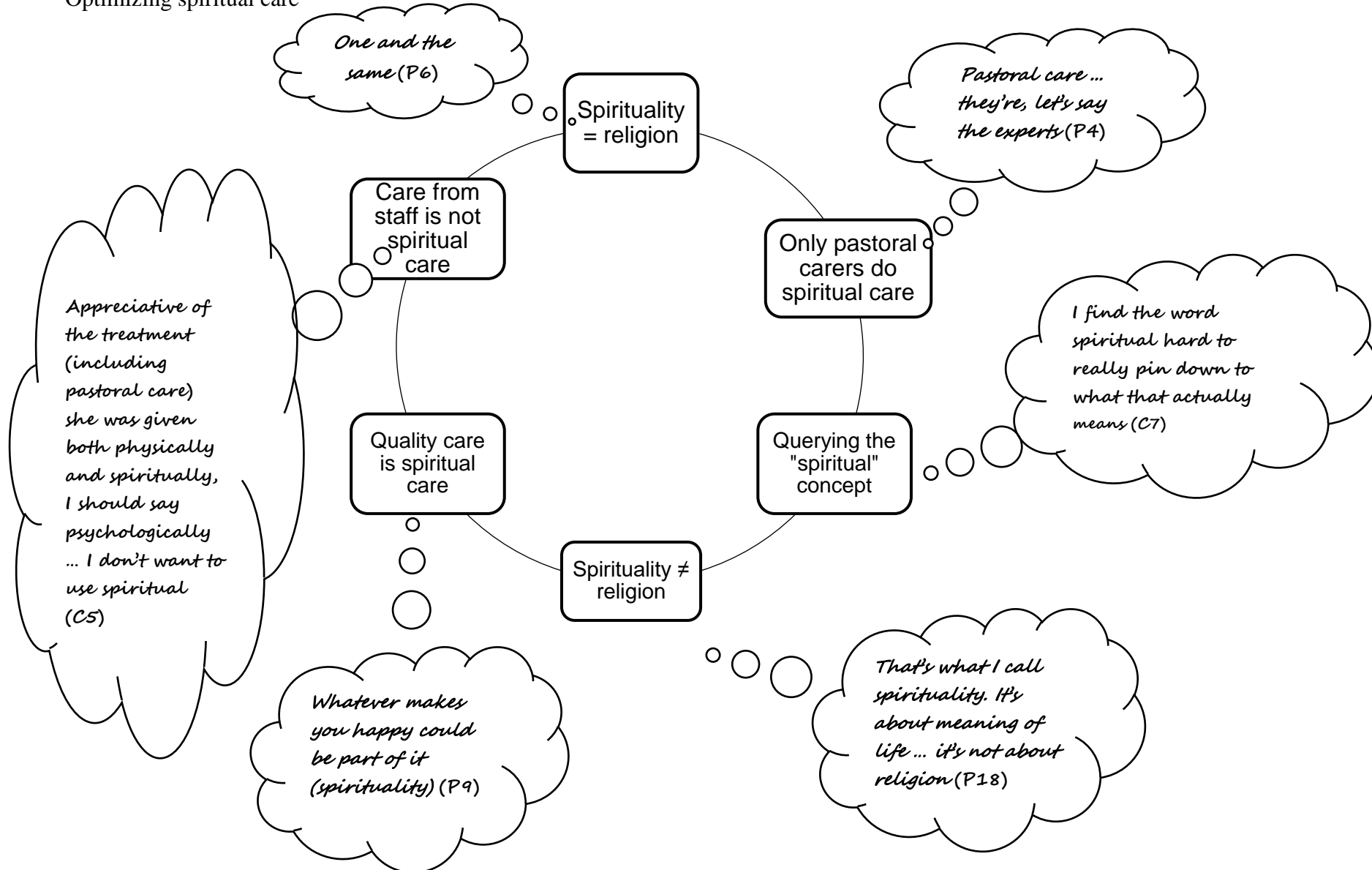
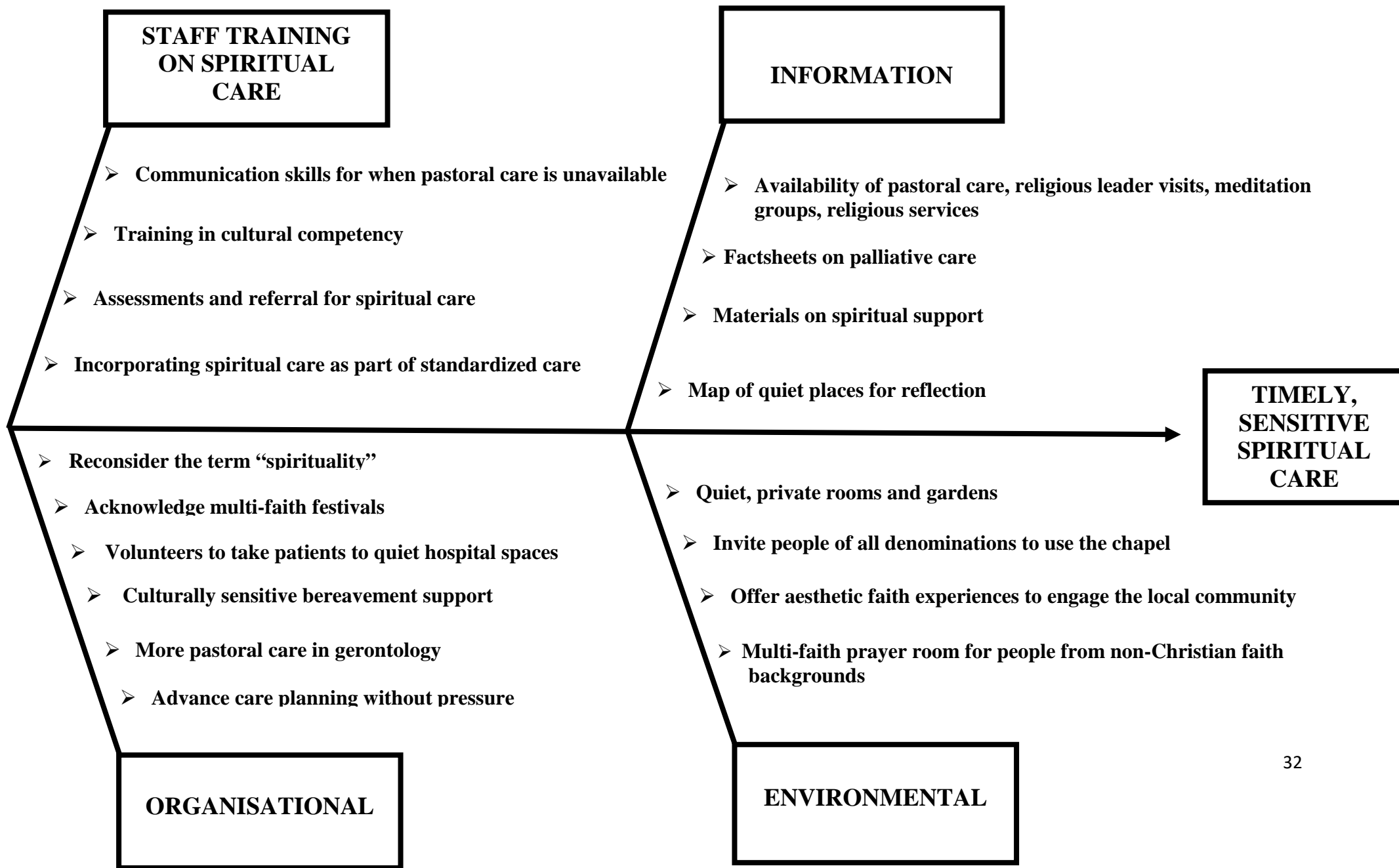


Fig. 2. Participants' mixed interpretations about spirituality and spiritual care.



Optimizing spiritual care

Fig. 3. Patients' and caregivers' recommendations to the health service [*Notes.* Each item informed by ≥ 1 participant; Participants either considered care items as spiritual care, or as reflecting the “what is important” component within the spiritual care definition]