DOI: https://doi.org/10.71317/kjard.2.11.2026.977

Kashmir Journal of Academic Research and Development

Journal homepage: https://rjsaonline.org/index.php/KJARD

Faith, Family and Finitude: A Phenomenological Inquiry into the Lived Experiences of Adults Facing Terminal Illness

Khizra Jamil
PhD, Clinical Psychologist, University of Karachi
Email: khizrajamil@hotmail.com
Namra Shahzadi
PhD, Assistant Professor, University of Gujrat
Email: Namra.shahzadi@uog.edu.pk
Misbah Arshad
PhD, Assistant Professor, University of Gujrat
Email: Namra.shahzadi@uog.edu.pk
Muneeb Ahmed Toor
PhD, Assistant Professor, University of Rasul
Email: Muneeb.toor@uorm.edu.pk

ARTICLE INFO

Received:
September 29, 2026
Revised:
October 14, 2026
Accepted:
October 26, 2026
Available Online:
November 05, 2026

Keywords:
Terminal illness, lived experience, phenomenology, religious coping,

Corresponding Author:
Muneeb Ahmed Toor
Email:
Muneeb.toor@uorm.edu.pk

ABSTRACT

Despite the above projections, there is a dearth of evidence from the perspective of the person facing the end-of-life in Muslims majorities and Urdu speaking communities in particular, where they experience suffering associated with serious health-related problems. Eight adult participants (six females and two males, ages 27-58 years) were recruited via convenience sampling and snowball sampling and interviewed in a qualitative phenomenological study. The interviews which were semi-structured were conducted in Urdu in the participants' homes and focused on nine domains: physical, psychological, and social experience; appreciation of life; self-transcendence; attachment to God; attitudes toward death; hope; and legacy. Thematic analysis based on a phenomenological approach was used to analyze transcripts. There were nine themes identified. They reported on multimorbidity, pain, disrupted sleep and loss of independence, anxiety (often about money), one episode of acute disorientation, and social worlds that were shrinking beyond the household. The act of devotion, thanking, and prayer were described repeatedly as sources of relief. Notions of death went from fear of death at night to trust in divine mercy, often in a single story. Patience and service, and passing on faith, were founded in the children, as was hope and legacy. The author does not depict the suffering and meaning as occurring one after the other, but side by side. The results are preliminary, as the sample was small and heterogeneous, and the prognosis was more liberal than usual, but they do confirm a holistic approach to care which regularly considers spiritual needs, family relationships and financial concerns. More longitudinal, larger, and caregiver-inclusive studies are required.

Introduction

In many ways medicine has succeeded in delaying death, but not eliminating it. Life expectancy continues to increase around the world, as does the number of individuals who will survive through periods of extreme illness. By 2060, approximately 48 million people will experience severe and disabling health-related suffering, nearly half of all deaths worldwide (47%), with the greatest increasing number of cases among older adults (70 years or older). (Sleeman et al., 2019) Those statistics are backed by a group of conditions where cure is no longer a reasonable hope – such as advanced cancers, end-stage heart, lung,

kidney, and liver disease, and advancing neurological disease. A person who has been told they are 'terminally ill', 'a person living with a life-limiting condition' or 'a person approaching the end of life' all have the same underlying meaning: the disease cannot be reversed, and death is now no longer abstract, but expected.

Rarely is such disease limited to the body. Distress close to the end of life tends to flow across symptom domains, which is one of the reasons why accounts of this distress are important for the specific disease (Gaertner et al., 2023), and is linked to pain and breathlessness, worry, role loss, strained relationships and questions about meaning. The loss of purpose, hope and identity which may follow a terminal diagnosis, has been correlated with despair as well as for hastened death, even in the absence of a diagnosis of depression (Breitbart, 2017). Concept analysis in advanced cancer likewise treats existential experience as a distinct domain of patient experience, separable from, yet entangled with, physical and emotional symptoms (Tarbi & Meghani, 2019).

The literature is not, however, exclusively about loss. Qualitative work with people confronting their own deaths describes accounts in which life became more meaningful, relationships were reordered, and ordinary goods were seen with new clarity (Kukla et al., 2022). Interviews with people affected by dying and by the idea of a “good death” suggest that, although dying is seldom described as beautiful, participants can still identify moments they regard as good (Heimerl et al., 2022). Whether such moments become reachable appears to depend partly on how a person copes. Resisting mortality has been associated with dysfunctional coping and heightened suffering (Wittkowski, 2016), whereas an accepting attitude may ease worry and make a good death more attainable (Heimerl et al., 2022). Anticipatory grieving, the experience of grief before an actual loss, has also been proposed as a buffer that shapes both the dying experience and later bereavement (Patinadan et al., 2022).

Spirituality sits at the centre of many of these accounts and, awkwardly, at the centre of some of the field’s unresolved problems. A consensus-oriented review of palliative care research found wide variation in how spirituality is defined and measured, and it called for work with more diverse populations (Steinhauser et al., 2017); a companion paper set out priorities for assessment and intervention (Balboni et al., 2017). Patients’ own descriptions of spirituality tend to be broader than formal religious practice (Fitch & Bartlett, 2019), although in devout communities the two may be hard to pull apart in daily life.

Two bodies of psychological work help to frame how faith operates when health fails. Research across Christian, Jewish, Muslim, Hindu, and Buddhist samples indicates that turning to the sacred under stress is common in every tradition, that positive forms of religious coping are reported more often than negative ones, and that the particulars of coping reflect each faith’s teachings (Abu-Raiya & Pargament, 2015). Attachment theory offers one account of why: when believers experience God as a safe haven and a secure base, faith can operate as a source of resilience (Cherniak et al., 2021). The link between religiosity and fear of death is considerably less tidy. A meta-analysis of 100 studies found only a weak negative association, substantial heterogeneity, and some support for a curvilinear pattern, and its authors asked for evidence from non-Western settings (Jong et al., 2018).

These questions carry particular weight in Muslim-majority societies. A systematic review of end-of-life care in such countries, which are home to much of the world’s estimated 1.7 billion Muslims, found that nearly all participants (97.6%) had advanced cancer and that most of the 30 included studies (22) were quantitative; the qualitative evidence pointed to selflessness, including worry about being a burden, ambivalence between hope and hopelessness, and strong beliefs about death, the afterlife, and closeness to Allah (Abdullah et al., 2020).

The whole of this work leaves a gap both empirically and conceptually. In practice, it seems that first-person accounts of patients suffering from non-cancer terminal illness from non-Western communities, which were conducted in people's own homes, are relatively rare. The four-dimensional description of the person (physical, psychological, social and spiritual) is generally accepted and has only rarely been explored in combination with meaning related constructs like “gratitude”, “self-transcendence”, “hope” and “legacy” in the same set of stories. The present study was undertaken to fill this gap.

We used an existential, phenomenological approach and applied the Attachment to God theory to spiritual situation, to describe the physical, psychological, social, and spiritual experiences, and the meaning making process of adults in terminal illness in the context of community living and their experience of Urdu language. The seven questions which guided the inquiry were: (a) How was the illness diagnosed and how does it affect daily activity and well-being; (b) How does it affect relationships with family and friends; (c) What are the effects on psychological health and the emotional state during the illness; (d) What coping mechanisms and strategies are used; (e) How is spiritual connection perceived and experienced during the illness; (f) What are the thoughts and feelings surrounding mortality and life after death; (g) What are the things they are grateful for and how do they hope to be remembered.

Methods

Research Design

A qualitative phenomenological design was used. The idea of phenomenology is to describe the meaning of a phenomenon as it is lived by people who experience it, without explaining or quantifying it (Neubauer et al., 2019). The phenomenon of interest was living with terminal illness. Because the question targeted first-person meaning connotations of the illness (what it feels like, what it requires, and what it means), this approach was suitable. The study was structured around the criteria for trustworthiness as outlined by Korstjens and Moser (2018) and the shortcomings of this study in relation to these criteria are discussed later.

Setting and Research Team

Interviews were conducted at the home of the participant. The decision was made to provide an environment that was familiar and comfortable, and would allow individuals with debilitating illness to discuss issues of distress without having to travel. The project was conducted by a group of psychology students in a research methods class working under the supervision of faculty, who individually recruited and interviewed participants within their community. Interviews were held in Urda.

Participants

Eight adults took part (six women and two men), aged 27 to 58 years. Seven were married and one was unmarried. Educational attainment ranged from no formal schooling and primary education to undergraduate and master's degrees. Before the onset of illness, most participants' occupations involved homemaking, manual labor, or professional work, and several had since changed or relinquished employment because of their condition. Participants received treatment in government, private, or other healthcare settings. Aggregate characteristics are presented in Table 1. Religious affiliation was not recorded on the demographic form; however, participants' accounts were consistently expressed in Islamic religious vocabulary, and this is treated as a feature of the data rather than as a verified sample characteristic.

Table 1

Characteristics of the Sample (N = 8)

Characteristic	Summary
Gender	6 women, 2 men
Age	Range 27–58 years
Marital status	7 married, 1 unmarried
Education	No formal schooling or primary education through undergraduate and master's level
Pre-illness occupation	Homemaking, manual labor, and professional work; several participants had changed or left employment because of illness
Treatment setting	Government hospitals, private hospitals, or other healthcare settings
Recruitment	Convenience sampling (primary); snowball referral for two participants
Interview setting	Participant's home
Conditions described in transcripts	P1: diabetes-related liver and cardiac failure with ascites. P6: long-term dialysis (about 15 years) with loss of mobility. P7: asthma, previous heart attack, diabetes. P8: severe arthritis with neurological symptoms. P2–P5: [authors to add]

Sampling and Sample Size.

The subjects were recruited primarily by convenience sampling, (i.e. individuals who met the criteria and were easily identified by team members) and then snowball sampling for two individuals who were referred by previous participants who had chronic illness. These strategies gave weight to access over diversity, and the sample should be interpreted as one that is rich in information, not representative. Eight was a practical number, influenced by the time spans of the courses. Larger numbers are drawn to the broad interview domains and the clinical diversity of the informants, while a narrow aim and rich interview dialogue work against that.Information power (Malterud et al., 2016) pulls in the opposite direction: the narrow aim and rich interview dialogue favor smaller numbers. Empirical work on saturation suggests that studies with focused objectives and relatively homogeneous samples often reach saturation within roughly 9 to 17 interviews (Hennink & Kaiser, 2022), and thematic saturation can be documented by tracking new information across successive interviews (Guest et al., 2020). Neither assessment was undertaken here, and we do not claim saturation.

Eligibility.

Eligible participants were aged 18 years or older, had a confirmed diagnosis of a terminal or life-limiting condition (for example, advanced chronic illness or end-stage organ failure), were aware of their prognosis, and were able to give informed consent and to take part in an interview, with or without assistance. The protocol specified a prognosis of more than one year, a criterion more permissive than conventional definitions of terminal illness; its consequences are considered in the Discussion. People were excluded if they had significant cognitive impairment such as dementia or delirium, were experiencing severe physical or emotional distress, or had a medical condition so unstable that an interview would be difficult or unsafe.

Measures

A structured demographic form recorded age, gender, marital status, level of education, occupation, residential status, and the type of facility (government hospital, private hospital, or other) from which treatment was received.Data were collected with a semi-structured interview guide covering nine domains: physical, psychological, and social experiences; appreciation of life; self-transcendence; attachment to God; attitudes toward death; legacy; and hope. Questions on physical, psychological, and social experience were developed from the World Health Organization Quality of Life instrument (WHOQOL Group, 1998). The existential and meaning-related domains (self-transcendence, appreciation of life, legacy, and hope) were informed by the Existential Meaning Scale, meaning-management theory, and existential positive psychology. Questions on spiritual belief and reliance on faith drew on attachment-to-God theory (Cherniak et al., 2021). Open-ended prompts invited participants to describe experiences in their own words and at their own pace, and the guide was administered in Urdu.

Procedure

Potential participants were approached, told about the purpose and procedures of the study and about their rights, and invited to take part. Written informed consent was obtained before any data were collected, and participants then completed the brief demographic form. Interviews took place at times convenient to participants and were paced according to their physical and emotional state; no one was pressed to answer or to continue. Participants were asked for permission to audio-record, and recording was carried out only for those who agreed. [Authors: state typical interview duration and describe how data were captured for participants who declined recording, for example, verbatim handwritten notes.]

Data Analysis

Recorded interviews were transcribed in Urdu, and transcripts were numbered by line so that every excerpt could be traced to its source; excerpts quoted in this article are English translations. Analysis proceeded in a phenomenological, thematic spirit. Transcripts were read repeatedly to gain a sense of the whole; statements bearing on each of the nine interview domains were identified; and these were grouped into subthemes that stayed close to participants' wording. A brief analytic commentary was then written within each domain, in which participants' own meanings (an emic reading) were juxtaposed with an interpretive, theory-informed reading (an etic one). The process is similar to the pattern-based theme development used in reflexive thematic analysis (Braun & Clarke, 2019) in which themes are seen as 'constructed' by the analyst rather than discovered in the data.

Rigor and Reflexivity

There are a number of features that help to establish credibility and dependability. Verbatim extracts, with line numbers, were used as an audit trail; interviews were conducted at participants' homes and in their own language, and multiple team members conducted interviews, which led to variation in interviewing stance, but also in technique. Phenomenological analysis relies heavily on the interpretation of the researcher and it is important to reflect on the team's assumptions (Dodgson, 2019). The team was made up of students using a common theoretical perspective and the existential and religious-coping frames in the

interview guide will have influenced what these students asked and heard. If member checking, independent double coding and/or formal saturation assessment have not been reported in the study protocol (or if they are not implemented), they are considered a limitation in accordance with the accepted trustworthiness criteria (Korstjens & Moser, 2018; Nowell et al., 2017).

Ethical Considerations

All were voluntary and the participants were not penalized for not answering a question or leaving the website. Prior to each interview, informed consent was obtained in writing and audio recording was only done with explicit consent, with no participant being coerced or forced to agree. All interviews were conducted with consideration for the physical and emotional conditions of participants. Confidentiality and anonymity was maintained, and participants are referred to only by numbers (P1–P8).

Results

The findings from the eight interviews are summarized into nine themes, one for each domain of the interview guide with three to four subthemes for each theme (Table 2). The themes were not categories that occurred spontaneously outside the influence of the questions, but are rather a structured description of what happened during the interviews in each of the domains. The participants are designated as number 1-8 and while the numbers in parentheses are line numbers in the Urdu transcripts from which the English excerpts were drawn.

Table 2

Themes and Subthemes Identified in Interviews with Eight Adults Living with Terminal Illness

Theme	Subthemes	Participants quoted
Physical experiences	Progressive deterioration and multimorbidity; functional limitation and dependence; sleep disruption and symptom burden; treatment, care, and religious practice	P1, P2, P3, P6, P7, P8
Psychological experiences	Anxiety, worry, and faith as refuge; acute distress and disorientation; resilience over time; coping through relationships, faith, and withdrawal	P1, P2, P4, P5, P6, P7, P8
Social experiences	Family devotion and shared caregiving; narrowing of the outer social circle; treatment fatigue and the therapeutic relationship	P2, P5, P6, P8
Appreciation of life	Gratitude for existence and blessings; relational contentment and fear of separation; accepting difficulty	P1–P8
Self-transcendence	Family roles as a source of meaning; reprioritization after illness; purpose and the cost of role-centered identity	P2, P6, P8
Attachment to God	Dependence and closeness; private disclosure and prayer as regulator; reinterpreting suffering	P2, P5, P6, P8
Death	Fear and acceptance; concern for those left behind; hope for mercy	P2, P3, P4, P6, P8
Hope	Relational and spiritual sources of hope; change across life stages; child-centered goals	P3, P6, P8
Legacy	Patience and love; service and empowerment; transmitting faith	P1, P2, P3, P4, P6, P7, P8

Note. P = participant. The nine themes correspond to the domains of the interview guide; subthemes were derived from participants' wording. "Participants quoted" lists those whose excerpts appear in the Results section, not all who contributed to a theme.

Theme 1: Physical Experiences

Physical experience ranged from stable routines held together by medication to multisystem failure. Some participants described illness as an accumulating sequence of breakdowns. P1 traced the path from diabetes to jaundice, to a failing liver, and then to cardiac insufficiency, repeated transfusions, and monthly drainage of abdominal fluid that in turn burdened the lungs (lines 1–10). P7 had received treatment for 10 to 12 years for asthma so severe that it required "nebulization even in washroom," had been hospitalized for twelve days unable to breathe, had suffered a heart attack, and also lived with diabetes (lines 920–928). P8 described severe arthritis that began with swollen joints and was later joined by "a brain issue" and "constant pain," with symptoms that had worsened after pregnancy (lines 1190–1215). Other participants mentioned marked weight loss, daily throat and neck pain, headaches, difficulty concentrating, and a weakness that led them to organize their days around conserving energy.

More often than any other, functional limitation was expressed, and this was expressed less in terms of movement than in terms of role. "It makes me feel useless sometimes, I can't prepare food for my family anymore, even talking is hard" (lines 117-119) said P2. P6, now in a wheelchair, said that he was helped with everyday tasks by his mother and wife: "At first it was easier, but now it is completely necessary for them to help" (lines 582–595). This dependency was difficult as he was once independent and did not have to work and provide for his family. Other participants said that they were able to function in their normal lives while they had their medication.

Differences were great in sleep and comfort. P1 reported that "I can't sleep, it feels like needles are prickling in my foot and in my stomach" and that she often found herself "overthinking" at bedtime (lines 22–24). In P2, there was frequent coughing that interrupted sleep, and the mind was active as well as the body from the worry about hospital costs (lines 120-122). P3, on the other hand, described a routine where he or she awakens at four or five in the morning, goes to bed at eleven or twelve at night, and heads outside to play after work, and complained of no insomnia or rest disturbances (lines 227-231).

Treatment experiences were generally, but not always, good. P6 was very happy with his doctor, having been all 15 years at the same dialysis centre, and said that free treatment is "a huge blessing", as he was not able to work (lines 608—616). He also described the difficulties for a transplant: Both his brothers were matches, one was too young and one was overseas (lines 598-607). P1 expressed relief at more potent remedies but had more and more trouble with wudu, prayer, and fasting (lines 18–21). In various reports, financial considerations at times made better medications unobtainable, and some report a greater confidence in private providers.

Theme 2: Psychological Experiences

Emotional life was marked by worry, much of it financial, and by the repeated use of faith as a place of refuge. P2 said, "Anxiety is my constant companion, especially regarding finance. But I find peace in the quiet hours of the morning when I pray. It's a brief, precious feeling of surrender" (lines 147–150). P6 described a quieter distress: he felt "a little lonely" when his children left for school in the morning, and peace returned when they came home (lines 688–700).

One account stood apart in its severity. P1 spoke of persistent tension and of feeling mentally very disturbed, and she recounted a night on which she became disoriented, was found by her sons in another room, and could recall nothing of the event: "I don't remember anything." Her sons, she said, had cried on seeing her in that state, and, "To this day, I don't understand what happened to me that night" (lines 39–54). Preliminary analysis described the episode as possibly dissociative; that label is treated as provisional here (see Discussion).

Some accounts traced a change over time. P6 recalled that when he first fell ill he worried about his future and felt that his "life was over," but that "as I continued to fight my illness, my life gradually started to get better." He now described gratitude, peace, and an absence of worldly worry, with one exception: "as a father I worry about my daughters and their future" (lines 666–687). Rather than a settled state, this appears to be a resolution that remained anchored to a single, specific concern.

Participants named several ways of managing distress. Relationships were the most common. P6 shared worries with his wife, who "comforts and reassures" him, and said, "Because of my family and friends, I feel much better" (lines 701–714). When upset, P1 sat quietly and her children tried to make her laugh or joke until she came to her senses (lines 59-62). When her sister and children spoke with her, P8 felt better (1274-1282) and P7 stated that she was better behaved since her family members took care of her (984-989). Spiritual practice was also common: P2 spoke about looking at pictures of her kids when they were young, and hearing the Qur'anic recitation, saying "reminds me that I'm fighting for something greater than myself" (lines 151–

154); P4 declared, “Whenever I feel upset, I offer prayers, pray to God, and recite the Quran” (lines 41–42). Withdrawal was a third approach. P5: Setting the phone aside, talking no one, playing slow music (lines 511-513).

Theme 3: Social Experiences

There was an amazing uniformity in accounts of the family. She said her husband had worked much longer than he could but was then driven to the hospital by her older son, while her daughter was running the household: “They are sacrificing their own lives for me, that's the most heartbreaking part, their love is my strongest medicine” (lines 27–31). His wife was his chief caretaker, being by his side at all times and taking him to dialysis, and in the second excerpt “gives him strength to live and fight this illness” (647–650) [authors: check the line range for the second excerpt (671-636 in the source)]. P8 had been supported by her husband though he was in straitened circumstances, but he never complained (lines 1233-1246). Caring was provided by spouses, children and parents, with actual hands-on care provided by relatives relatively close to the family and by others further away who would call, remind, encourage or send money.

Social worlds were more restricted than the household. I don't go out with family anymore, I hardly call people on the phone anymore, I don't want to see my friends looking at me weak, it's isolating” (lines 137–139) P2 said. In place of the community that was all once together, “now everybody keeps a distance from others” (lines 499–501) said P5. P6 was more differentiated: his family and family members were still the same; some of his friends were no longer around; friends in other countries were there still, supporting him in a emotional and financial way; his best friends were still the same (lines 651-662).

Several transcripts included summaries indicating that therapy may be tiring; some participants expressed frustration and wanted to discontinue therapy, while others showed a high satisfaction with therapy and strong relationships with their physicians. One participant was not as sociable before being ill due to caregiving and other household responsibilities, which helped to remind others that isolation can have more than one source.

Theme 4: Appreciation of Life

Gratitude was expressed in all of the interviews and was primarily to Allah. P2 reported, ‘I'm most thankful for the love of my family, for the few wonderful moments that I have with my kids, for the gift of sight and hearing, and I really appreciate that more than now' (lines 186-189). P3, P4 and P6 expressed thanks for the course of their lives (323-326), marriage and children (452-455) and many “colors of life” they have lived to see (826-838). Gratitude wasn't about circumstances: P8 said, “My life was full with a lot of worries but I'm still thankful to Allah for bringing me to this life” (lines 1407-1413).

Appreciation was also in the relational sense. Lines 67–74: P1 spoke with satisfaction about a successful marriage, a husband who had cared for her during sickness, and children who she had raised, married and had seen prosper in business. Relational anchoring, however, created fear: P7 commented, “We are afraid of separating from children,” (lines 1077–1087) and P8 expressed pride and relief that her children did not “go astray” (lines 1414–1423).

The third strand was to embrace the challenge. “The difficult times made me stronger and taught me the value of the good times” (line 193–195) is P2's response to that. P5 said that the hardship hits all people, rich or poor, and that things are up to Allah (553-557). P6 described himself living “with patience and gratitude,” never losing hope (849-857), and P8 thought that her continued life was linked to her being grateful in sickness and in health (1423-1433). Hardship was then often expressed in terms of a test or lesson, not just as bad luck.

Theme 5: Self-Transcendence

For some of the participants, meaning was found in family roles. “My value is no longer in my career, my value is in being the mother and wife that held our family together” (lines 155-159), P2 says. Illness could also redirect priorities. P6 said he felt invulnerable in his early years but when he got ill, “I started to appreciate life.” He had previously had bad habits (smoking, cold drinks and restaurant food), but now avoided them, and had a good diet “mostly for the sake of my children” (lines 715–732). His stated aims, to keep his wife happy and to see his daughters educated, well raised, and settled, had intensified since marriage and parenthood (lines 733–745).

The cost of this role-centered identity was visible in P8’s account. Married at 16 or 17 and without formal education, she had devoted herself to her children’s success, yet her son’s schooling ended after the eleventh grade because “battling the illness or educating the children, it was one or the other” (lines 1316–1345). Looking back, she said, “I’ve seen a lot of pain in my life,” described telling her daughters not to come near her because their presence made her cry, and concluded that “if Allah gives me life, I’ll spend it in His worship, and that’s when my life will have importance” (lines 1283–1315). She also found satisfaction in teaching cooking, sewing, and crochet to neighborhood children.

Theme 6: Attachment to God

Several participants described illness as drawing them closer to God. P2 characterized her relationship as one of "absolute dependence": "I've been stripped of my own strength, so I have nothing left but to depend on Him. I feel closer to God now than ever have before" (lines 167–170). P6, who had always prayed, said that after illness his relationship with Allah had become much stronger: "There are certain things that I can only discuss with Allah, and doing so brings me peace" (lines 757–766). Remembrance (zikr) had become a tool for hard moments.

Prayer also served as a private channel for distress. P5 wanted to trust in Allah more than putting their worries into people's mouths because when they speak to people they will share it with others and it makes them worry but with Allah, his worries leave their heart, and Allah gives them peace and shows them the solution (lines 525–529). At the end of P8, prayer was the first response to anxiety: "Even if its hard for me to breath I pray. That's the only way I feel peace" (lines 1355-1358).

There were also changes in belief regarding God. He has now learnt gratitude and he is more patient and his biggest prayer is forgiveness of his shortcomings in the past (lines 786–795). P8's was a more mixed picture. She said that she complained with Allah a little, then she rebuked herself: "Who am I, a sinful human, to complain against God?" She was convinced that this trial had been brought upon her by her own misfortunes, by a providential test and by the Devil (Shaiytan) himself, who "tries to distract us from our devotion to God" (lines 1359-1374). Her account, therefore, contained more than one explanation, and there was self-correction that accompanied complaining.

Theme 7: Death

There were mixed attitudes towards death and mixed within participants. When P6 reflects on death, he feels fear, particularly at night; that the people would abandon him in the grave and be unable to assist him, because "no one else will be able to help me except my deeds." He could no longer pray, so he was afraid of the repercussions, but he took comfort from a hadith that, in his knowledge, frees the sick person from judgment (lines 796–813). In his previous narration, he had reported that death was not something he considered (lines 666-687), which seems to contradict this.This is in contrast to his previous narration where he stated that death was not something that he would think about because "life and death are in Allah's hands" (lines 666-687). P3 voiced a more matter-of-fact ambivalence: "Whose heart desires to die? "Everyone's heart wants to live," she says, "We do have faith in death, don't we?" (lines 304–308). Concern often turned outward. P8 asked, "What will happen to my children after I'm gone?", worrying especially about her daughters' loneliness, and then silenced the thought: "Go away, Satan! My God is with me, and I won't think about such things" (lines 1387–1401). P4, by contrast, said, "I believe that what's written in your destiny can never be changed," and reported no worry about the future (lines 445–448).

Thoughts of what follows death centered on mercy. P3 said, "No one knows what happens after death. Everyone hopes for Allah's mercy," and that people try to do the least wrong in the time left (lines 314–322). P2, speaking as a Muslim, believed in the Day of Judgment and hoped "for God's mercy and a peaceful place where there is no pain and no struggle" (lines 183–185).

Theme 8: Hope

Hope was described as something received from others and from God more than something self-generated. P6 traced a progression: when illness began, parents, siblings, and friends assured him that he would recover; after marriage his wife encouraged him; and now, he said, "my children have become the light of hope for me" (lines 858–877). He added that looking at his children, especially his daughters, brought peace and motivated self-care (lines 871–877). P3 said that "a father's biggest motivation is his children," and that "only the sense of responsibility" was carrying him forward, since some life tasks were complete and others were not (lines 340–349).

Faith and family converged in P8's account: her sister and children told her to stay hopeful, and she added that "it's hope that keeps a person alive" (lines 1437–1448). Goals were child-centered. P6 hoped that his children would finish their education and that his daughters would marry well (lines 878–883), while P3 acknowledged that many goals had been met, others remained, and he was "waiting" for them (lines 354–358).

Theme 9: Legacy

When asked how they hoped to be remembered, participants spoke of character and relationship far more than of achievement. P1 said, "My children will remember my patience" (lines 104–105). P3, a father, reasoned that "every child remembers their father," and that those he supported would miss him (lines 359–364). Service was a second strand. P8 taught sewing to girls in her neighborhood and refused payment because "I want these girls to succeed and remember me fondly in their lives" (lines 1453–1465). P2 had likewise taught skills to other women "so they could earn money" and had listened to anyone who needed

an ear (lines 209–211), and P4 said that “help comes from Allah—we only try to be a means of help” (line 473). P7 named her family’s love as the source of her strength to fight illness (lines 1144–1146).

The third strand was the transmission of faith. P3 wanted his children to be successful “both in religion and in the world,” and gave advice on prayer and fasting (lines 374–382). P6 wished to leave his children “the gift of the Qur’an,” hoped that his daughters would memorize it, and intended to leave them a special share of his property so that they would never face hardship (lines 895–908).

Discussion

The primary purpose of this study was to explore the physical, psychological, social and spiritual context in which adults with terminal illness live and their experiences of death, life and hope for the future. The overall sense from the nine themes is one of simultaneousness rather than succession between hardship and meaning. The one who had felt useless because she no longer had the responsibility of cooking for her family also found her value in having held the family together and the man who was afraid of going to the grave at night was talking about surrendering to God's will. Coexistence with such a nature is hard to monitor with symptom checklists, and this was one of the reasons for using a phenomenological approach. The findings are interpreted in light of the existing literature, with the note of caution that this is not generalizable because it is based on eight interviews.

People's physical records verify that death or end-of-life illness is not one-organ disease. Diabetes, liver, cardiac, respiratory, rheumatological and renal problems all occurred alone and synergistically, and the spectrum was broad enough to be uninformative for conclusions regarding the individual diseases (Gaertner et al., 2023), as noted in the argument that conclusions should be drawn for each disease individually. Of the latter, one pattern was relatively constant: the bodily symptom was rarely reported by itself. Coughing interfered with sleep (P2) and so did worrying about hospital bills; there was a needling sensation and night-time rumination (P1) that arrived together. The entanglement reflects the wider perspective that distress in advanced illness is multi-dimensional and that there is a case for not separating the physical and psychological aspects of illness management.

The one most salient psychological discovery was the role. Cooking, working or providing was reported to make a person feel “useless” (P2) or it was an “unwanted dependency” on others who relied on the participant before (P6). These experiences are consistent with existential distress related to the loss of purpose and identity (Breitbart, 2017; Tarbi & Meghani, 2019). Importantly, the excerpts analyzed do not include any reference to a desire to speed death, but the guide did not inquire directly about it and the missing references should not be interpreted as evidence of missing references.

It is worth of a separate comment to describe the experience of P1 becoming disoriented at night and unable to remember what had happened. The initial investigation found it dissociative and the dissociative language might be appropriate. However, P1 also noted a liver failure and multiple other serious issues, and organic causes such as metabolic issues, drug use, etc. are not ruled out with clinical data. Delirium was an exclusion criterion, and thus an acute confusional state was not expected in the sample. Labeling is therefore provisional and we see this episode as a reminder that studies of clinical aspects of this population should provide a means to refer an unexplained concern.

The most commonly reported resource was religious practice, which could be represented using existing categories. Prayer, recitation, and remembrance as reactions to anxiety is consistent with the finding that people across religious traditions, including Muslim samples, use positive religious coping to a high degree (Abu-Raiya & Pargament, 2015). Being “stripped of my own strength” (P2) – being dependent on God alone – and being “confided in Allah what can not be known to others” (P6) – trusting in Allah rather than in others – are similar to the type of attachment where God is a secure base and safe haven (Cherniak et al., 2021). There is no way that our data enable us to assert whether this orientation was caused by illness or enhanced by it; in P6's case he explicitly stated that he had always prayed, and in his words it was a matter of strengthening, not conversion.

There are three qualifiers. First, faith wasn't a balm for everyone. P8's complaint was interrupted by self-reproach; sometimes she blamed herself, sometimes the Divine and sometimes the Devil for her suffering, and P6 feared what would happen to her if she were no longer able to pray. These patterns can be better characterized as spiritual struggle and religious coping rather than a lack of struggling and a lack of religious coping. Second, there were also some spiritual losses such as the inability to perform wudu, prayer and fasting (P1) – this is a deprivation that one would not see in a conventional symptom assessment. Third, the desire to rely on Allah over others (P5) was partly attributed to a fear of gossip, to the extent that religious coping can sometimes serve to substitute for what is perceived as unavailable in the social domain. What can be said in the preliminary commentaries on these data, which is often claimed as evidence of prayer efficacy, is only speculation, as none of the interviews test a physiological mechanism.

Last but not least, there can be norms within the devout communities regarding the manner of the suffering's being discussed. Gratitude and acceptance may be sincere and also socially acceptable, and when both occur in a same expression (e.g., P8's expression of gratitude, his weeping, and his withdrawal), a certain level of caution is warranted in interpreting any single expression as a whole. These observations correspond with the Muslim majority evidence-based findings of closeness to Allah, ambivalent hope and hopelessness and selflessness as recurring themes, with the additional inclusion of first-person descriptions of these conditions not being cancer-related (Abdullah et al., 2020). They also endorse the concept of spirituality research that involves the use of clearly defined constructs and more diverse populations (Steinhauser et al., 2017) and that assesses and intervenes in a systematic manner (Balboni et al., 2017).

Family was the central theme and organizing principle of the participants' social world: they were cared for by family, received financial support from family, got transportation from family, had emotional support from family, and, in many stories, they had an explanation for why to keep going from family. The participant's strongest medicine was the love of their family, immediately followed by distress over the sacrifice of members' lives (P2). No one else could help P6, and he did not ask his employed brother either. This ambivalence seems to mirror the theme of selflessness, such as concerns about being a burden, found in the Muslim majority review (Abdullah et al., 2020), and it also serves as a reminder that a protective resource may also lead to feelings of guilt. Other half of this relationship is not reflected in our data because caregivers were not interviewed.

The pattern was contraction, outside the household. Attendance at gatherings was reduced, calls were made to fewer people, or participants became aware of a waning interest from family and friends, though some friendships remained strong, especially with close friends and friends overseas. As far as we can tell, shrinking was motivated both by physical factors and the desire not to be perceived as weak (P2). This is not a picture of abandonment, and it is possible that some withdrawal was desired and not forced. But the interviews did not seek to ask about this distinction, so it remains an open question.

Fears and acceptance of death were not neatly divided. P6's answer in relation to thinking about death and his fear of the grave at night are examples of how the ideas of acceptance and anxiety may coexist, and that different positions may arise at various times in the interview context. This is in line with a meta-analysis that found a weak and heterogeneous association between religiosity and death anxiety (Jong et al., 2018). It is also in line with the perspective that resistance and acceptance slide into each other (Wittkowski, 2016). Some participants (P3, P8) appeared to be more concerned about someone else's death rather than their own, as they were wondering about the future of their children after they were gone.

Hope and legacy co-existed and both were linked to children and faith. Hope was described as a sense of responsibility (P3), early, relational with parents and siblings, and later with spouse after marriage, and even with children (P6). This aligns with descriptions of family resilience that emphasize the importance of relationships and mutual shared belief in creating meaning, hope, and transcendence (Walsh, 2020). Legacy statements were about being patient, serving and imparting religious knowledge rather than about wealth or achievement, consistent with Erikson's (1963) notion of generativity, and also consistent with terror management accounts, in which symbolically being able to carry on through valued relationships or worldviews serves to regulate the awareness of mortality (Pyszczynski et al., 2015). The latter reading is theoretical, and we do not test and differentiate among these frameworks with our data.

Likewise, the omnipresence of thanks ought to be taken as a modest statement. While a few of the studies relating gratitude to well-being and health are experimental, most are foundational and correlational (Jans-Beken et al., 2020), in this sample gratitude had to be coupled with a theistic frame. It is encouraging that some participants reported valuing life more after falling ill, as this is the meaning gain reported by Kukla et al. (2022). It is important to keep in mind that the sample was not representative of those in a state of severe distress, but rather of those willing and able to be interviewed, so there may be a greater representation of adaptation than originally thought.

The theory and applications of the Subject will be discussed.

Theoretically the nine domain structure substantiates the usefulness of a multidimensional model but indicates that there is something missing. In these stories, the relational and generative element (children, caring, teaching, inheritance) served as a link between the physical, psychological, social and spiritual rather than a stand-alone one – role loss resulted in psychological suffering for the individual, caring for family served as a buffer, and caring for children influenced both hope and fear of death. If the four domains are considered to be parallel, a relational-generative axis may be needed, if not in most family-centered communities, then at least explicitly. The attachment perspective also seems to be useful for articulating the use of faith as a refuge, though with the addition of those concepts that capture struggle and self-blame.

In practice, there are four implications that are tentatively suggested. First, spiritual and existential evaluation should become part of the routine care of those dying from conditions other than cancer and should go beyond belief to ability to believe, such as by asking people if they can pray, perform ablutions or fast because of their illness, and by consulting religious advisers for

practical accommodations. Secondly, care must be family-inclusive, family caregiver strain focus, and must pay attention to the children's future; this is the same as the concept of palliative care focusing on anticipatory grief and dignity (Patinadan et al., 2022) and the concept of meaning based care which asks the questions of meaning and purpose as an active therapeutic material (Breitbart, 2017). Third, financial anxiety, that was experienced by several accounts, requires a clinical response such as social work or subsidised treatment. Fourth, there should be a procedure in place for clinicians and researchers to assess acute confusion/disorientation in home-based chronic illness care.

Strengths and Limitations

Strengths of the study include the collection of firsthand accounts in the participants' own homes and language, the inclusion of a broad spectrum of domains, and the presence of individuals who had more than one chronic condition other than cancer. It also has significant restrictions and they should temper all of the above interpretations. It was small, convenience- and snowball-sampled and clinically heterogeneous, making it impossible to make diagnoses or demographic comparisons within it; and religion was not formally recorded. The prognosis of the protocol (over one year) is more general than typical definitions of a terminal illness, with one participant describing a stable and active lifestyle and others experiencing 10-15 years of living with illness. The results therefore apply to life with life-limiting illness rather than to actual death and the term “terminal” should be interpreted as such. Excluding the extremely distressed may have eliminated those that were most distressed. Different student researchers conducted interviews and may have had varying methods, some interviews were recorded and some were not, and translation between Urdu and English may have changed the meanings and nuances. Documentation of formal member checking and double coding and of saturation assessment were not included. Some of the comments were interpretative in nature (e.g., physiological effects of prayer, or dissociation). Finally, the themes were somewhat prefigured by the questions that were asked and six of the eight participants were women, so any conclusions about gender differences in role-based meaning are precluded.

Conclusions and future recommendations

In the study, adults with terminal illness spoke of failing bodies, diminishing roles and futures beyond their control, but they also spoke of gratitude, being close to God, being devout and having their hope placed in their children. A sense of suffering and of meaning seemed to go hand in hand. The main idea is that care for such patients may not be limited to symptom management; spiritual practice, family relations and financial concern are part of the patient's experience. These conclusions can only be tentative, due to the size of the sample, the methods used for selection and the scope of the prognosis criterion.

The following are some ideas for future research in light of the limitations. (a) Larger, purposively sampled maximum variation studies should include stratification by diagnosis (e.g., end-stage kidney disease, heart failure, cancer) plus a clinically determined prognosis of 12 months or less, and include a balance of genders and urban and rural residence. Longitudinal designs where there are repeated interviews at diagnosis, three months and six months could investigate the changes in hope, attitude towards death and attachment to God as the disease progresses. (d) Dyadic or family interviews, with caregivers, would open up the conflict between loving and burdening that emerged here. (d) Mixed methods work could involve the use of narratives alongside the reporting of validated measures of spiritual well-being, religious coping, meaning, depression, anxiety and death anxiety, reflecting calls for validated outcomes measures in spirituality studies (Steinhauser et al., 2017). Reflexive Journaling, independent double coding, member checking, and documented saturation tracking should be incorporated into the studies (Guest et al., 2020). Finally, a culturally adapted, home-based, family-inclusive intervention based on meaning centered and dignity oriented approaches (Breitbart, 2017; Patinadan et al., 2022) could be co-designed with patients, caregivers and religious advisers and tested for feasibility and acceptability prior to a test of effectiveness.

References

Abdullah, R., Guo, P., & Harding, R. (2020). Preferences and experiences of Muslim patients and their families in Muslim-majority countries for end-of-life care: A systematic review and thematic analysis. *Journal of Pain and Symptom Management, 60*(6). https://doi.org/10.1016/j.jpainsymman.2020.06.032

Abu-Raiya, H., & Pargament, K. I. (2015). Religious coping among diverse religions: Commonalities and divergences. *Psychology of Religion and Spirituality, 7*(1), 24–33. https://doi.org/10.1037/a0037652

Balboni, T. A., Fitchett, G., Handzo, G. F., Johnson, K. S., Koenig, H. G., Pargament, K. I., Puchalski, C. M., Sinclair, S., Taylor, E. J., & Steinhauser, K. E. (2017). State of the science of spirituality and palliative care research part II: Screening, assessment, and interventions. *Journal of Pain and Symptom Management, 54*(3), 441–453. https://doi.org/10.1016/j.jpainsymman.2017.07.029

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health, 11*(4), 589–597. https://doi.org/10.1080/2159676X.2019.1628806

Breitbart, W. S. (Ed.). (2017). *Meaning-centered psychotherapy in the cancer setting: Finding meaning and hope in the face of suffering*. Oxford University Press. https://doi.org/10.1093/med/9780199837229.001.0001

Cherniak, A. D., Mikulincer, M., Shaver, P. R., & Granqvist, P. (2021). Attachment theory and religion. *Current Opinion in Psychology, 40*, 126–130. https://doi.org/10.1016/j.copsyc.2020.08.020

Dodgson, J. E. (2019). Reflexivity in qualitative research. *Journal of Human Lactation, 35*(2), 220–222. https://doi.org/10.1177/0890334419830990

Erikson, E. H. (1963). *Childhood and society* (2nd ed.). W. W. Norton.

Fitch, M. I., & Bartlett, R. (2019). Patient perspectives about spirituality and spiritual care. *Asia-Pacific Journal of Oncology Nursing, 6*(2), 111–121. https://doi.org/10.4103/apjon.apjon_62_18

Gaertner, J., Zimmermann, F., & Simone, C. B., II. (2023). The value of patient reported outcomes in palliative radiotherapy: A discussion in light of current findings. *Annals of Palliative Medicine, 12*(3), 611–615. https://doi.org/10.21037/apm-23-147

Guest, G., Namey, E., & Chen, M. (2020). A simple method to assess and report thematic saturation in qualitative research. *PLOS ONE, 15*(5), Article e0232076. https://doi.org/10.1371/journal.pone.0232076

Heimerl, K., Schuchter, P., Egger, B., Lang, A., Frankus, E., Prieth, S., Kaelin, L., Dinges, S., Wegleitner, K., & Reitinger, E. (2022). "Dying is never beautiful, but there are beautiful moments": Qualitative interviews with those affected on the subject of "good dying." *Mortality*. Advance online publication. https://doi.org/10.1080/13576275.2022.2034773

Hennink, M., & Kaiser, B. N. (2022). Sample sizes for saturation in qualitative research: A systematic review of empirical tests. *Social Science & Medicine, 292*, Article 114523. https://doi.org/10.1016/j.socscimed.2021.114523

Jans-Beken, L., Jacobs, N., Janssens, M., Peeters, S., Reijnders, J., Lechner, L., & Lataster, J. (2020). Gratitude and health: An updated review. *The Journal of Positive Psychology, 15*(6), 743–782. https://doi.org/10.1080/17439760.2019.1651888

Jong, J., Ross, R., Philip, T., Chang, S.-H., Simons, N., & Halberstadt, J. (2018). The religious correlates of death anxiety: A systematic review and meta-analysis. *Religion, Brain & Behavior, 8*(1), 4–20. https://doi.org/10.1080/2153599X.2016.1238844

Korstjens, I., & Moser, A. (2018). Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *European Journal of General Practice, 24*(1), 120–124. https://doi.org/10.1080/13814788.2017.1375092

Kukla, H., Herrler, A., Strupp, J., & Voltz, R. (2022). "My life became more meaningful": Confronting one's own end of life and its effects on well-being—A qualitative study. *BMC Palliative Care, 21*, Article 58. https://doi.org/10.1186/s12904-022-00950-3

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research, 26*(13), 1753–1760. https://doi.org/10.1177/1049732315617444

Neubauer, B. E., Witkop, C. T., & Varpio, L. (2019). How phenomenology can help us learn from the experiences of others. *Perspectives on Medical Education, 8*(2), 90–97. https://doi.org/10.1007/S40037-019-0509-2

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods, 16*(1), 1–13. https://doi.org/10.1177/1609406917733847

Patinadan, P. V., Tan-Ho, G., Choo, P. Y., & Ho, A. H. Y. (2022). Resolving anticipatory grief and enhancing dignity at the end-of-life: A systematic review of palliative interventions. *Death Studies, 46*(2), 337–350. https://doi.org/10.1080/07481187.2020.1728426

Pyszczynski, T., Solomon, S., & Greenberg, J. (2015). Thirty years of terror management theory: From genesis to revelation. *Advances in Experimental Social Psychology, 52*, 1–70. https://doi.org/10.1016/bs.aesp.2015.03.001

Sleeman, K. E., de Brito, M., Etkind, S., Nkhoma, K., Guo, P., Higginson, I. J., Gomes, B., & Harding, R. (2019). The escalating global burden of serious health-related suffering: Projections to 2060 by world regions, age groups, and health conditions. *The Lancet Global Health, 7*(7), e883–e892. https://doi.org/10.1016/S2214-109X(19)30172-X

Steinhauser, K. E., Fitchett, G., Handzo, G. F., Johnson, K. S., Koenig, H. G., Pargament, K. I., Puchalski, C. M., Sinclair, S., Taylor, E. J., & Balboni, T. A. (2017). State of the science of spirituality and palliative care research part I: Definitions, measurement, and outcomes. *Journal of Pain and Symptom Management, 54*(3), 428–440. https://doi.org/10.1016/j.jpainsymman.2017.07.028

Tarbi, E. C., & Meghani, S. H. (2019). A concept analysis of the existential experience of adults with advanced cancer. *Nursing Outlook, 67*(5), 540–557. https://doi.org/10.1016/j.outlook.2019.03.006

Walsh, F. (2020). Loss and resilience in the time of COVID-19: Meaning making, hope, and transcendence. *Family Process, 59*(3), 898–911. https://doi.org/10.1111/famp.12588

WHOQOL Group. (1998). The World Health Organization quality of life assessment (WHOQOL): Development and general psychometric properties. *Social Science & Medicine, 46*(12), 1569–1585. https://doi.org/10.1016/S0277-9536(98)00009-4

Wittkowski, J. (2016). Coping and attitudes toward dying and death in German adults. *OMEGA—Journal of Death and Dying, 72*, 316–339. https://doi.org/10.1177/0030222815575283

2026 by the authors; Journal of *Kashmir Journal of Academic Research and Development*. This is an open access article distributed under the terms and conditions of the Creative Commons Attribution (CC-BY) license (http://creativecommons.org/licenses/by/4.0/).