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# Advanced cancer patients' experience and perception of advance care planning at a university teaching hospital in Northern Tanzania

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## Abstract

**Background:** Advance care planning (ACP) is not formally implemented in Tanzanian healthcare. While the burden of non-communicable diseases continues to rise, most patients present at advanced stages of illness, highlighting the urgent need for ACP to support preference-based care.

**Objectives:** This study aimed to explore advanced cancer patients' experiences and perceptions of ACP at a university teaching hospital in Northern Tanzania. Findings may inform the contextual relevance and acceptability of ACP tools in low-resource settings.

**Methods:** This qualitative study employed individual in-depth interviews with eight patients diagnosed with advanced cancer at Kilimanjaro Christian Medical Centre. Participants received a translated version of the Five Wishes document to read and discuss with their families at home prior to the interviews. A phenomenological approach guided the data collection and analysis. Interviews were conducted in Swahili, transcribed verbatim, translated into English, and thematically analyzed using an inductive coding process by two researchers.

**Results:** Four key themes emerged: (1) nature of acceptance, (2) challenges to uptake and utilization of ACP, (3) modality and timing of conversations, and (4) strategies for effective integration into clinical care. While initial hesitation was common, participants generally found ACP relevant and valuable for family harmony, future preparation, and quality of life.

**Conclusion:** Despite limited awareness and sociocultural taboos around death, ACP was viewed as meaningful by patients with advanced illness. Further studies are needed to evaluate culturally appropriate adaptations and implementation strategies for ACP in the Tanzanian context.

## Keywords

advanced cancer, advanced care planning, end of life, experience, palliative, perception, Tanzania

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## Introduction

Advance care planning (ACP) refers to the process through which individuals express their preferences for future healthcare, especially in situations where they may no longer be able to make decisions themselves. Globally, the "Five Wishes" document—an accessible advance directive—has gained popularity for facilitating such discussions in clinical and non-clinical settings.[1,2]

While ACP is widely recognized in high-income countries, its uptake and implementation in low- and middle-income countries (LMICs), including those in sub-Saharan

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Africa, remain limited.[3] Several contextual barriers—such as sociocultural taboos around death, limited awareness of palliative care, and the lack of enabling legal and institutional frameworks—hinder effective ACP implementation.[4-6] Nevertheless, regional studies from South Africa[7] and Rwanda[8] have begun to explore how ACP can be integrated into culturally distinct and resource-constrained healthcare systems. In Tanzania, the concept of ACP is not formally integrated into clinical care pathways or health policy.[9]

Existing studies in Tanzania, including Gafaar et al.,[9] have highlighted the cultural complexity around end-of-life conversations and perceptions of a "good death." These studies also point to the absence of structured communication between patients, families, and health professionals regarding end-of-life preferences. Moreover, a recent study by Mushi et al.[10] showed that while patients with advanced cancer expressed willingness to receive palliative care, systematic communication around future care remains underdeveloped.

At Kilimanjaro Christian Medical Centre (KCMC)—a tertiary referral hospital in Northern Tanzania and one of the country's few cancer treatment centers—many patients present at late stages of illness.[11] Based on clinical experience and observation, and in the absence of institutional guidelines for end-of-life conversations, patients' preferences for care are often not discussed, documented, or followed. This underscores the need for context-sensitive approaches to ACP in Tanzanian oncology and palliative care settings.

This study is, to our knowledge, the first to explore how Tanzanian patients with advanced cancer experience and perceive ACP by a translated version of the Five Wishes document. The findings aim to inform future efforts toward contextually appropriate ACP frameworks and contribute to the global discourse on ACP from an African LMIC perspective.

## Methods

### Study design

This study employed a qualitative descriptive design informed by phenomenological principles to explore the lived experiences and perceptions of patients with advanced cancer regarding ACP. A phenomenological lens allowed us to capture participants' subjective understanding of preparing for end-of-life care within their sociocultural context.[12] Data were analyzed using Braun and Clarke's six-step thematic analysis framework, which supports an inductive, reflexive approach to theme development.[13]

### Setting and participants

The study was conducted at KCMC, a tertiary university hospital in Northern Tanzania and one of five designated cancer care centers in the country.[14] The oncology unit at KCMC provides both curative and palliative services, but currently lacks structured protocols for documenting or discussing advance directives. Participants were purposively sampled from the oncology clinic between April and May 2022. Inclusion criteria were: (1) aged 18 years or older, (2) confirmed diagnosis of stage III or IV cancer, (3) physical and mental ability to participate in a 30–40 min interview, (4) attendance at a minimum of two follow-up consultations, (5) living with family members, (6) literacy in Kiswahili, and (7) willingness to engage with advance directives. Exclusion criteria included patients attending the clinic for the first time, those too ill to participate, and those who declined to provide written consent. "Readiness" to participate was assessed through clinician judgment and informal pre-interview conversations with the researcher. Participants were considered ready if they demonstrated emotional stability, comprehension of the topic, and willingness to reflect on end-of-life preferences. Of the 11 cancer patients given the Five Wishes documents, 8 turned out to agree to participate. Follow-up phone call and live conversation at the oncology clinic, fear of being involved in death talks, immigration, unwillingness of family members to discuss, and severity of illness were the reasons for their refusal or non-participation during the study period.

### Interview tool and cultural adaptation

The semi-structured interview guide (see supplemental material) was developed based on literature related to ACP, palliative care in LMICs, and prior implementations of the Five Wishes document.[2,3,5,6,9,10,15,16] It focused on the perceived usefulness, challenges, and cultural appropriateness of ACP. Two pilot interviews were conducted to refine the questions and language before final implementation in the study area. Participants were given a Kiswahili-translated version of the Five Wishes document during a clinical consultation. They were encouraged to read it and discuss it with their families at home over a 2-week period. No formal cultural adaptation was performed. However, the researcher provided oral explanations in Kiswahili and answered questions to support understanding. Healthcare staff were not involved in the interviews or analysis.

### Data collection

All face-to-face interviews were conducted in Swahili by the first author (A.A.M.), a trained palliative care nurse, in a private consultation room with individual participants. Family members were excluded from interviews to ensure the participants' freedom of expression. Each interview was conducted once, lasted between 30 and 45 min, and was audio-recorded with permission. Interviews were transcribed verbatim in Swahili, translated into English,

**Table 1.** Sample characteristics.

| Participant | Sex | Age (years) | Education | Marital status | Type of cancer | Cancer stage |
|---|---|---|---|---|---|---|
| P01 | F | 49 | Primary | Divorced | Rectal | IV |
| P02 | M | 64 | Primary | Married | Kaposi's | IV |
| P03 | F | 47 | College | Married | Breast | IV |
| P04 | F | 53 | Primary | Married | Breast | IV |
| P05 | M | 82 | Primary | Married | Prostate | IV |
| P06 | F | 56 | Secondary | Married | Breast | IV |
| P07 | F | 51 | Primary | Married | Breast | IV |
| P08 | M | 70 | Secondary | Married | Prostate | IV |

and de-identified to ensure confidentiality. Before ending the interviews, participants validated the interview notes, and the researcher noted any clarifications or additions. Data saturation was reached after eight interviews, with no new themes emerging.

### Data analysis

Thematic analysis followed Braun and Clarke's six-step process: (1) familiarization with data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the report.[13] Two researchers (A.A.M. and M.N.I.) independently and manually coded the transcripts using an inductive approach. Coding was first discussed jointly on four transcripts, after which each researcher proceeded independently. A third researcher (F.S.) reviewed the final themes for consistency and confirmability. Coding was conducted manually, and the development of the codebook was iterative and collaborative. An audit trail was maintained to ensure transparency in collection and analytical decisions, with the addition of the COREQ checklist for presentation of qualitative findings.

## Results

Eight participants were interviewed (three men, five women), aged between 47 and 82 years. All had stage IV cancer, with the majority diagnosed with breast ($n=4$) or prostate ($n=2$) cancer. Most (seven of eight) were married, and five had attained primary-level education, which typically corresponds to 7 years of schooling in Tanzania. For detailed characteristics, see Table 1.

Thematic analysis yielded four major themes, four subthemes, and two analytical categories, derived from 32 distinct codes (see Table 2). These are presented below with supporting quotations and frequency references (e.g. "six of eight participants") to illustrate representativeness.

### Nature of acceptance of ACP

Participants' reactions to ACP ranged from initial discomfort to eventual appreciation. All eight participants found aspects of the Five Wishes relevant, though five explicitly stated initial shock or anxiety. However, seven of eight participants described ACP as meaningful for preparing emotionally, maintaining family harmony, and reducing distress at the end of life.

One participant explained:

> It was difficult, but in the end, as a family, we saw how the Five Wishes can help us create harmony, cope with situations, and prepare for the worst. . . I am ready to use it and can advocate for others too. (P01)

Participants associated ACP with the ability to "clear things" with family, express personal values, and ensure that loved ones are not left confused or burdened. In this context, "autonomy" was described not in individualistic terms, but in relational terms—through joint decision-making with spouses and children. For example:

> If I can't talk, and only my wishes are followed, I can feel being valued, cared, respected. I can die without grievances. (P06)

Six of eight participants said they would prefer to die at home rather than incur unnecessary hospital costs, although some expressed doubts about the feasibility of home-based care.

> If I am going to die, why admit me in the ward and stress with cost management? It's better I die peacefully at home near my family and spare that money for them. (P05)

Yet four participants also acknowledged that home care might not be realistic due to complications or limited medical support. This tension between preference and reality is discussed further below.

### Challenges for uptake and utilization of ACP

All eight participants acknowledged barriers to initiating or sustaining ACP discussions. These included cultural taboos around death, emotional distress, and family-centered decision-making. In particular, three of five female participants expressed hesitation about making

**Table 2.** Final themes, subthemes, categories, and codes.

| Themes | Subthemes | Categories | Codes |
|---|---|---|---|
| Nature of acceptance | Perceived relevance in care | | Clear information |
| | | | Contextual feasibility and care-appropriate |
| | | | Advocacy for others |
| | Perceived importance | Future preparation | Family peace and harmony |
| | | | Grief coping and acceptance of death |
| | | | Trust between clients and HCPs built |
| | | | Compliance with treatment improved. |
| | | | Wish description stimulated |
| | | | Realistic goals are set |
| | | Improved QoL | Relieved distress and suffering |
| | | | Peaceful death attained |
| | | | Reduced unnecessary costs |
| | | | Preference-based care |
| | | | Ensured dignity |
| Strategies for effective incorporation into healthcare | | | Frequent sensitization during consultations |
| | | | Inclusive family discussion |
| | | | Good approach and therapeutic language |
| | | | Recognition by country laws and health policy |
| | | | Availability of clinical guidelines |
| | | | Adequate community education |
| | | | Further studies to come up with a contextual-appropriate framework |
| Challenges for uptake and utilization of ACP | | | Readiness for utilization |
| | | | Limited self-decision-making power |
| | | | Fear of involvement in death talks |
| | | | Distrust among individuals |
| | | | Misconceptions about disease causation |
| | | | Lack of community knowledge |
| Modality of conversations | Timing for initiation | | Number of consultations consideration |
| | | | Stages of disease considerations |
| | Improper timing for initiation | | Loss of hope |
| | | | Suicidal ideation and attempts |
| | | | Distrust in medical care |

ACP: advance care planning; HCP: health care provider; QoL: quality of life.

decisions without their husbands' consent, reflecting the relational—and often gendered—nature of autonomy in the Tanzanian context.

> Even if I agree, I dare not use it without my husband's consent. You know I am a woman. (P07)

Six of eight participants described family members reacting negatively to the Five Wishes document, with some interpreting it as a sign that the patient was "giving up." One participant explained:

> My kids cried when I showed them the document. They wanted me to withdraw from the study. Even if I'm ready, they will make the right decision—out of love. (P08)

Cultural beliefs about illness causation also created skepticism toward ACP. Two participants worried that surrendering decision-making could open the door to manipulation or even harm.

> You may find yourself surrendering your life to someone who is behind your illness. And it costs you in the end. (P08)

These responses reflect deep-seated community-level distrust in the medical system, and the absence of culturally grounded ACP frameworks likely intensified such concerns.[17]

## Modality and timing of conversations

Opinions varied on when and how ACP should be introduced. Five of eight participants advocated for early conversations—preferably after diagnosis but before physical decline. They emphasized the need to "think while still strong."

> It gives me more time to think and adjust my decisions if I do it before I get worse. (P05)

However, three participants believed ACP should only be introduced when recovery is no longer possible. One woman highlighted the emotional risks of early disclosure:

> If told there are still chances for cure, it's hard to also say, "Oh, you need to write your wishes." Better concentrate on treatment first, then bring it in slowly. (P07)

Improper timing, according to four participants, could lead to loss of hope, avoidance of care, or even suicidal thoughts. As one participant put it:

> Some may hate the hospital forever. . . or just give up and die earlier. (P04)

These reactions may stem not only from timing but also from limited palliative care integration and lack of training in sensitive communication strategies.[18]

### *Strategies for integration of ACP into clinical care*

Participants proposed several strategies for improving the uptake of ACP:

- Repeated sensitization during consultations (six of eight participants)
- Family-inclusive conversations (five participants)
- Public awareness campaigns (radio, community meetings, religious institutions)

> Frequent sensitization during consultations and in the community can help people see its importance. (P02)

Participants emphasized that when all family members understand the diagnosis and ACP process, acceptance improves, and stigma decreases. One woman noted:

> When they are around, they can accept and support my decisions more easily. (P04)

The lack of formal policies was also raised. Three participants believed ACP should be legally recognized and regulated:

> These things require putting your trust in someone. The law should ensure that one's wishes are protected—even when unconscious or after death. (P03)

Finally, participants called for more research and culturally adapted frameworks for ACP in Tanzania, warning that Western tools, such as Five Wishes, may not fully fit local beliefs and structures.

## Discussion

This study explored the experiences and perceptions of advanced cancer patients regarding ACP in a tertiary hospital setting in Northern Tanzania. Our findings reveal that, despite initial discomfort and limited familiarity with the concept, participants ultimately valued ACP as a tool to maintain family harmony, prepare emotionally for death, and reduce uncertainty. These findings contribute new insights from an underrepresented context and underscore the need for locally adapted ACP frameworks in sub-Saharan Africa.

While ACP is increasingly practiced in high-income settings, its implementation in low-resource environments remains limited and context-dependent.[19,20] Rather than transplanting models such as the Five Wishes document into culturally distinct contexts, our findings suggest that ACP should be reimagined in a way that reflects communal values, shared decision-making, and spiritual or family-based notions of autonomy.[21,22]

### *Relational autonomy and cultural beliefs*

Participants' perspectives challenged individualistic notions of autonomy that underlie many Western ACP tools. Several women deferred decision-making to husbands or adult children. Rather than reflecting disempowerment, this behavior may represent a form of relational autonomy deeply embedded in family structures.[23,24] In African contexts, involving family in care decisions is often considered essential to dignified dying and spiritual completeness.[25]

Healthcare providers must, therefore, learn to navigate and support this relational process while ensuring that patients' voices are heard. Effective ACP in Tanzania must balance cultural expectations of family involvement with ethical safeguards against coercion or economic pressure.

### *Death as a taboo and the role of health systems*

Participants often associated ACP with fear, emotional distress, and societal discomfort. While this might appear as a cultural resistance to discussing death, it also reflects the lack of palliative care integration in the Tanzanian health system. Where terminal diagnoses are poorly communicated and palliative services underdeveloped, death remains shrouded in denial and silence.[26]

Introducing ACP without strengthening palliative care may amplify confusion or distress. Conversely, integrating ACP within broader community-based palliative care programs can normalize end-of-life conversations and strengthen trust in medical systems.[27]

### ACP timing and communication

There was no consensus among participants on when ACP should be introduced. While some favored early discussion, others preferred to delay such conversations until the prognosis became terminal. These divergent views highlight the importance of flexibility and timing, especially when delivering emotionally charged information.

Participants' descriptions of losing hope or contemplating suicide after receiving the Five Wishes document underline the need for training in communication skills among healthcare professionals. As in other LMICs, Tanzanian clinicians often lack structured training in palliative communication.[28] ACP discussions should be sensitive, staged, and responsive to patients' emotional readiness.

### Resource constraints and unrealistic expectations

Some participants hoped that ACP would reduce the costs of hospitalization and allow for death at home. While ACP can align care with patient preferences, this presumes that community-based or home-based palliative services are available and equitable. In reality, Tanzania lacks structured systems for home-based end-of-life care, especially in rural areas.

Without additional infrastructure and caregiver support, encouraging home death could lead to unintended suffering or abandonment. ACP should not be framed as a cost-saving measure, but as a process to promote dignity and appropriate care. Any promise of reduced burden must be carefully contextualized.[29]

### Limitations of the Five Wishes tool

Although the Five Wishes document served as a conversation starter, its format and language may not fully reflect Tanzanian values. Participants encountered confusion, mistrust, and even social stigma. This illustrates the limits of applying Western ACP instruments in LMICs without formal cultural adaptation. ACP tools should be co-developed with local stakeholders and pilot-tested across different ethnic and religious groups.[30]

### Implications for practice

This study suggests that ACP is acceptable and meaningful to Tanzanian patients with advanced illness—when introduced with care and contextual sensitivity. Clinicians should:

- Recognize the central role of families in decision-making,
- Initiate ACP discussions progressively, based on patients' readiness,
- Integrate ACP into broader palliative care and community education initiatives,
- Receive structured training in culturally competent communication.

Efforts to implement ACP in Tanzania must go beyond legal frameworks and engage health systems, faith communities, and patients themselves.

### Strengths and limitations

This is the first study in Tanzania to explore ACP perceptions among cancer patients using qualitative interviews. It offers important insights for future policy and implementation. However, some limitations must be acknowledged:

- Only patients with advanced cancer were included, excluding other terminal illnesses.
- The Five Wishes tool was translated but not formally culturally validated.
- Family members and healthcare providers were not interviewed.
- Although data saturation was reached with eight participants, findings may not be generalizable beyond similar clinical settings.

We addressed trustworthiness through triangulated coding, reflexivity, and adherence to COREQ standards. Nonetheless, future studies should expand to include caregivers and diverse populations.

## Conclusion

Despite sociocultural barriers and limited prior exposure to ACP, patients with advanced cancer in Tanzania valued the opportunity to reflect on and express their wishes. Relational autonomy, emotional readiness, and culturally grounded communication emerged as central themes. Future research should co-develop locally tailored ACP tools and explore implementation strategies that align with Tanzanian values, family structures, and healthcare realities.

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## Ethical considerations

Ethical approval was obtained from the Kilimanjaro Christian Medical University College Research Ethics and Review Committee (Cert. No: 2540). Institutional permission was granted by KCMC (Ref. No. KCMC/P.I/Vol.XII).

## Consent to participate

Participants first gave oral consent when receiving the Five Wishes document and provided written consent at the time of the interview. Each participant was assigned a pseudonym (P01–P08), and all data were anonymized to ensure confidentiality.

## Author contributions

**Anna A. Massawe:** Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Resources; Writing – original draft.
**Manji N. Isack:** Conceptualization; Formal analysis; Methodology; Writing – original draft.
**Heather Drury-Smith:** Conceptualization; Formal analysis; Methodology; Supervision.
**Furaha Serventi:** Conceptualization; Formal analysis; Validation.
**Blandina T. Mmbaga:** Conceptualization; Methodology; Project administration; Supervision.
**Oliver Henke:** Conceptualization; Methodology; Formal Analysis, Writing; Supervision – review & editing.

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## Data availability statement

The data supporting the findings of this study can be retrieved from the corresponding author upon reasonable request.

## Supplemental material

Supplemental material for this article is available online.

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