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Qualitative Study

RESEARCH ARTICLE

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Exploring Patients' and Families' Perceptions of Family Meetings in Oncology: A Qualitative Study

Fadi Fayyad Fawaris[1]*, Rufaida Ibdah[2], Elham H Othman[3], Sobuh Abu Shanab[4], Jumana Yousef[5], Mahmoud Abunasser[4], Mohammad Farhan[6], Ahmad Abu Alfwares[7]

Abstract

Background: Communication in healthcare settings is vital for patient safety and quality of care, affecting outcomes including anxiety levels, satisfaction, and medication adherence. **Aim:** This study explored patients' and family members' perceptions of the family meeting process in inpatient palliative care. **Methods:** An exploratory qualitative study was conducted using semi-structured individual interviews with family members of seriously ill patients recruited purposively from a nonprofit community hospital. Interviews were conducted in person between July 2010 and March 2011. Data were analyzed using thematic analysis following phenomenological approach. **Results:** Twenty-four respondents provided 118 significant statements. Four main themes emerged: (1) the distinctiveness of family meetings, (2) the blind transition and family readiness, (3) the impact on decision-making process, and (4) setting expectations and clarifying care goals. Conclusion: Family members reported that discussions with the inpatient palliative care team resulted in improved communication and knowledge, which contributed to enhanced decision-making ability.

Keywords: Family meetings- palliative care- communication- decision-making- qualitative research

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Introduction

Communication in all healthcare settings is vital for patient safety and quality of care [1]. Effective communication affects different care outcomes such as anxiety level, patient satisfaction, clinical outcomes, and medication adherence [2, 3]. Patients and their caregivers need clear information related to their disease process, prognosis, symptom management, treatment plan, and end-of-life care decisions, in a manner that allows patients the opportunity to finalize interactions and maintain meaningful connections with loved ones [4, 5].

When these communication needs are met through structured and supportive approaches, there is a noticeable improvement in emotional well-being, quality of life, and psychological outcomes for both patients and family members [6]. Families often face challenging decisions when caring for a terminally ill loved one. Enhancing communication with family members, especially the primary caregiver, can help reduce negative perceptions and potentially lessen psychological distress [7]. Integrating family members into advance care planning may enhance patient autonomy, facilitate shared decision-making, and contribute to the delivery of care that is both individualized and consistent with the patient's values and preferences [8].

Palliative care is a holistic care approach provided by a multidisciplinary team that focuses on both the patient and their family [9-11]. Effective and standardized communication between patients, their families, and healthcare providers is necessary to provide the best possible palliative care outcomes. One of the available and applicable methods of facilitating communication is a family meeting, also referred to as a family conference or shared decision-making session. Family meetings between the patient, their family, and healthcare professionals may be conducted for many purposes including conveying information, discussing goals of care and diagnosis, treatment, prognosis, and developing a care plan strategy. Furthermore, family meetings can identify unmet needs [4, 12, 13].

Previous Research on Family Meetings and Communication

Several studies have explored the challenges and benefits of communication in palliative care settings. A qualitative study of 20 semi-structured interviews with social care staff found that staff expressed difficulty supporting people around death and dying, tending to

*[1]Emirates Health Services, United Arab Emirates. [2]Ministry of Health, Jordan. [3]Applied Science Private University, Jordan. [4]King Hussein Cancer Center, Jordan. [5]Al-Kindi Hospital, Jordan. [6]St. John's Riverside Hospital, United States. [7]AL-Balqa Applied University, Jordan. *For Correspondence: Fadi.fawaris@ehs.gov.ae*

avoid communication about death. The study identified factors that particularly influence staff practice around communicating death-related bad news: (1) fear and distress around death; (2) life and work experience; and (3) organizational culture. Staff attitudes to death communication had a stronger influence than their clients' level of cognitive or communicative abilities, and managers had strong influence through their role as role models [14].

A phenomenological study exploring the challenges of ethical communication faced by social workers in their daily practice with families and other health professionals in a pediatric hospital context in Australia used semi-structured interviews with nine social workers [15]. The study explored participants' perspectives that they perform two main roles in communication: supporting families and facilitating communication within healthcare provider teams. Five challenges had obvious impact on communication: participants faced ethical difficulties when withholding information from patients, the need to mediate between the patient, family, and healthcare professionals to share information, difficulty bridging between what the physician said and what families understood, numerous individuals involved in giving information, and systems and processes presenting barriers [15-17].

Focus group meetings with nurses at a pediatric intensive care unit aimed to characterize the nature and extent of nurse involvement in family meetings in the intensive care unit, recognizing obstacles to nurse participation and incentives for participation. The findings described three main themes explaining the engagement of nurses in family meetings: nurses may play multiple roles in supporting family meetings, nurses face crucial obstacles in the fulfillment of these roles, and nurses end up as mediators in family meetings. These findings showed that nurses need more education and more commitment to empowerment of patients and to promote the relationship between nurse and physician in family meetings [18].

A qualitative study using face-to-face in-depth interviews and observations examined whether and how the steps of shared decision-making can be recognized in decision-making about second- and third-line chemotherapy. The study indicated that patients were satisfied with the decision-making process, but the steps of shared decision-making were hardly seen in daily practice. The conception of awareness about available treatment choices by physicians was inadequate and not discussed in an equal way. The wishes and fears of patients were not specifically addressed, resulting in different expectations of enhanced survival from subsequent chemotherapy lines. The researchers concluded that there are many ways to facilitate communication with patients through open and honest dialogue, especially when discussing patients' expectations and concerns, and physicians should explain all treatment options, including forgoing treatment, and communicate the risks of benefit and harm [4].

A study aimed at explaining the design and assessment of an existential communication course program targeting general practitioners suggested that patients with cancer primarily want to address existential problems as part of clinical care, but that general practitioners lack confidence when addressing existential issues in daily practice. Training programs are needed to improve the ability of the medical team to communicate confidentially and to convey existential communication [19].

A qualitative study conducted with 51 encounters between doctors and patients aimed to characterize outpatient communication in a major cancer hospital in southern China with regard to the structure, style, and focus of doctor-patient communication. The results showed that outpatient communication was characterized by structured conversation, doctor domination of the conversation, and a focus on technology during communication. These characteristics imply that there is significant inequality of power between Chinese doctors and patients at the individual and institutional environment level. The researchers concluded that continued education and professional communication skills training are needed to improve communication [20].

In a qualitative study conducted in an academic medical center with 20 cancer patients and eight physicians involved in cancer care, which aimed to explore patient and physician perceptions of shared decision-making in clinical encounters for cancer care, the results indicated that most physicians reported providing patients with written information. However, patients reported that written information was too detailed and they expressed that the physicians did not evaluate the level of information they wanted to receive. Most patients wished to play an active role in the treatment decision [21].

Significance of the Study

Despite the importance of family meetings for delivering information and goal clarification in palliative care, there is a shortage of published literature describing the optimal timing of initiated meetings, who should participate, and how they should be conducted to demonstrate the utility of family meetings or the best way to evaluate them. Organizations need to assess medical team abilities to conduct family meetings and to explore the facilitators and barriers to conducting meetings. This study contributes rich data that will improve the effectiveness of family meetings and may determine a guide for effective family meetings.

Study Goals

The goals of this study were to: 1. Explore patients' and family members' perceptions of the family meeting process in inpatient palliative care 2. Identify the key elements that contribute to effective family meetings 3. Understand the challenges and barriers experienced during the transition to palliative care 4. Examine how family meetings impact decision-making processes

Materials and Methods

Setting

The study was conducted at King Hussein Cancer Center, a nonprofit community hospital in Jordan.

Design

An exploratory qualitative study was conducted using individual interviews, a well-suited method for collecting rich, subjective data on perceptions and opinions concerning the quality of healthcare services. This approach is particularly effective in eliciting detailed emotional responses and opinions from participants, addressing a gap in the literature regarding family members' experiences with palliative care. The study is reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines.

Sample

The palliative care team conducted purposive recruitment of family members following the palliative care consultation. Eligible participants were over 18 years of age, able to communicate effectively, and had participated in at least two family meetings within the palliative unit. To reduce the burden and distress on families, individuals of patients nearing death (as determined by the palliative care physician) and those experiencing significant emotional trauma related to the patient's condition (as assessed by the clinical psychologist) were excluded from the study.

All but one family member agreed to participate, and recruitment continued until thematic saturation was reached. The final sample consisted of 24 family members. Participant characteristics are presented in Table 1. The sample was diverse, with participants ranging in age from 22 to 72 years (mean age 42 years, SD 14.38). More than half of the participants were female (n=16), while males made up the remainder (n=8). The sample was well-educated, with 33% having some college education, 50% holding bachelor's degrees or higher, and 4% possessing graduate degrees. In terms of relationship to the patient, participants were primarily siblings (29%), sons or daughters (33%), spouses (29%), grandchildren (8%), and parents (9%).

Table 1. Demographic Characteristics (n = 24)

Characteristic	Participants
Age (years)	
Mean age (SD)	42 (14.38)
Gender (n (%))	
Male	8 (33%)
Female	16 (67%)
Highest grade in school (n (%))	
Some college	8 (33%)
Bachelor's degree and more	12 (50%)
Master and doctorate	1 (4%)
Missing	1 (4%)
Relationship to patient (n (%))	
Parent	2 (9%)
Son/daughter	8 (33%)
Spouse	7 (29%)
Sibling	7 (29%)
Grandchild	2 (8%)

Instrument

Semi-structured interview protocols were developed based on literature review and expert consultation. The interview guide included open-ended questions exploring family members' experiences with family meetings, their perceptions of communication with the palliative care team, their understanding of information provided, and their involvement in decision-making processes.

Data Collection

The clinical psychologist introduced the study to potential participants, and after obtaining their consent, researchers reached out to family members to schedule interviews. These interviews were conducted by a researcher with a master's degree in psychiatric and mental health, who had extensive formal and informal training in qualitative research and experience conducting both personal interviews and focus groups. The interviewer had no prior contact with participants.

Interviews were held within a week of the initial palliative care consultation, either in person at the hospital or over the phone, and lasted 30 to 60 minutes. With participant permission, the interviews were audio-recorded, transcribed verbatim, and entered into a spreadsheet for analysis.

Data Analysis

Thematic analysis was conducted following Colaizzi's phenomenological method. The process involved:

1. Reading all transcripts to obtain a general sense of the data
2. Extracting significant statements from each transcript
3. Formulating meanings from significant statements
4. Organizing formulated meanings into themes
5. Integrating themes into an exhaustive description of the phenomenon 6. Validating findings with participants

The respondents in this study provided 118 significant statements. From the interpreted meanings, four central themes emerged that capture the family members' experiences during family meetings.

Ethical Considerations

This study was approved by the Institutional Review Board (IRB) at King Hussein Cancer Center. Written informed consent was obtained from all participants prior to their involvement in the study. To ensure participants' emotional well-being, a dedicated psychologist was available during all interviews to provide psychological first aid if needed. All procedures were conducted in accordance with ethical standards and guidelines for research involving human participants.

It was emphasized to all participants that they had the right to decline participation in the study, and stringent confidentiality measures were implemented to protect their privacy. The study consistently upheld the fundamental ethical principles of beneficence, non-maleficence, autonomy, and justice to ensure the well-being and safety of the participants.

Results

Four overarching themes emerged from the data analysis: (1) distinctiveness of the family meeting, (2) blind transition and family preparedness, (3) impact on the decision-making process, and (4) setting expectations and clarifying care goals. Participants highlighted both positive and negative aspects of the palliative care (PC) family meeting for consults or referrals.

Theme 1: Distinctiveness of Family Meeting

The uniqueness of the family meeting was evident, and various aspects of the Palliative Care (PC) team stood out distinctly. Participants compared the PC team's characteristics to their experiences with other teams within the same hospital. Specific attributes noted included the communication style, which involved a more compassionate and intimate tone during conversations, ample opportunity for exchange, and enhanced access to physicians and other medical team members. This encompassed providing sufficient time for family meetings, follow-up consultations, and sharing contact information for PC team members to address any inquiries.

One participant described interactions with the PC team as entirely distinct from other care providers, stating:

"*It's a whole different experience.*" (Brother)

One participant described interactions with the Palliative care (PC) team as completely different compared to other care providers. They appreciated the PC team conducting conversations with more privacy, especially when meeting with family members. The participant also emphasized the importance of body language cues in the conversation, noting that the physician's demeanor conveyed decision-making authority. Another individual initially preferred not to hear detailed information about their spouse's condition but changed their mind once the PC team started the conversation, appreciating the empathetic approach and feeling comfortable participating in the decision-making process.

Overall, the quality of discussions provided a comfortable environment for some patients and their families. The PC team typically spent 1-2 hours during family meetings, with follow-up as necessary, and participants appreciated the unhurried nature of these meetings. Access to the PC team, including their availability for questions 24/7, was also seen as a valuable form of support. One family member highlighted the importance of ongoing guidance and understanding the essential needs before discharge.

The discussions were viewed as interactive rather than one-sided, allowing for questions and discussions from family members. Participants felt that the PC team paid attention to patient preferences and involved them in decision-making. This patient-centered approach was new for some, requiring adjustment. One family member mentioned learning about their mother's attitude towards care and allowing her to have a greater say in her treatment. The PC team was perceived as supporting the patient and family in obtaining the necessary information to make informed decisions, and participants believed that the team would support whatever choice the patient and family ultimately made.

Theme 2: Blind Transition and Family Readiness

Participants interviewed stated that the transition to palliative services was not adequately explained, and healthcare workers needed a better understanding of the family's needs during this transition to palliative care. A daughter stated:

"*I felt shocked when the palliative care team visited me to make sure if I'm accepting the palliative referral; that was the first time I heard about palliative care.*" (Daughter)

Furthermore, participants recognized that organized transitions to a palliative care approach early in the patient's disease trajectory, supported by policy and guidelines, were rarely evident during the transition. On the other hand, the timing was recognized as a distressing problem. The participants stated that the transition to a palliative care approach typically occurred when the patient was close to death, which gave the participants a negative impression about the palliative approach.

"*At the beginning, I hated the palliative team. However, after some time, I began to think that a key reason for this issue might be the hospital's focus on acute medicine.*" (Family member)

Another issue that arose from the interviews was family members' willingness to gain information. Family members indicated varying levels of preparedness, ranging from wishing to have this conversation sooner to being completely unprepared. The level of acceptance of the team's information by family members appeared to be connected to preparedness.

According to one participant:

"*We would have wanted to have had a heads-up about it since, because my mother was so depressed, the phrase 'hospice' scared her quite a bit.*" (Daughter)

Because the consultation was not well scheduled and families were only notified that the PC team would meet them, one participant described it as "*kind of harsh timing; we waited*" (Son). Another participant stated her lack of preparation for the meeting: "The PC team discussed the situation with my little daughter who is 16 years old. That is so depressing!" (Patient). Another respondent expressed feeling "*shocked*" (Father).

Theme 3: Impact on Decision-Making Processes

Participants highlighted several aspects of the consultation that affected their ability to make informed choices about their family member's care. The receipt and consistency of information, as well as clear discussions about care options, played a significant role in their decision-making.

The interprofessional palliative care (IPC) team

offered thorough information about the illness, its progression, treatment options, and end-of-life care. For many family members, this information about palliative care was new. The PC team introduced new alternatives and eliminated previously known ones. Some families admitted being unfamiliar with hospice and palliative care services prior to the consultation, while others had their preconceived notions about hospice care challenged. The consultation served as an educational opportunity to learn about available services and care options.

However, contradictory information from healthcare teams, including the PC team and the primary care physician, left some family members overwhelmed and unprepared to make decisions. Information and support from the palliative care (PC) team facilitated acceptance for some families, even if they felt pressured to accept the new approach.

The PC team played a crucial role in facilitating care decision-making and developing a plan to achieve desired care outcomes. They helped bring families together on a common goal of care, particularly when family members had diverse and conflicting care goals. Participants expressed a sense of enlightenment, having a plan for action, and feeling better about understanding the situation.

The focus of clinical care shifted from aggressive treatment to prioritizing comfort and quality of life for critically ill patients. Family members emphasized the importance of providing compassionate care and ensuring their loved ones received the desired care in their preferred setting. Pain management was identified as a key area addressed during the IPC consultation.

Participants valued the holistic approach of the PC team, which went beyond traditional medical care by addressing both physical and emotional issues. This was particularly beneficial for individuals resistant to being treated by a psychiatrist.

Theme 4: Setting Expectations and Clarifying Care Goals

The findings demonstrate that involving patients and their family members in communication regarding the care plan enables them to express their objectives and allows the Palliative Care (PC) team to reaffirm the goals of care. One patient stated that the treatment plan means what healthcare providers explained to them, emphasizing the importance of clear communication. Another participant expressed full confidence in the discussion with the PC team, indicating their satisfaction with the communication process.

A family member praised the PC team for their excellent job in explaining and counseling both the patient and the family members, which created a high level of comfort. However, one spouse remained focused on the aspect of pain management during the PC consultation, hoping for a cure. They believed that the explicit objective of the PC team was to manage pain and support the patient's recovery. Despite the absence of a discussion on cure or recovery during the consultation, this spouse continued to prioritize those outcomes.

On the other hand, some participants felt rushed and unprepared during the PC consultation. They believed that the consultation should have taken place earlier in the progression of the disease. Having the PC consultation at the time of diagnosis was seen as beneficial, as it would have provided clarity and guidance during a confusing period. Several participants expressed the desire to receive information earlier in the process, as it would have allowed them to be more involved in the decision-making process and explore alternative care options.

Discussion

This qualitative study identified four themes that describe family involvement in the Interprofessional Palliative Care (IPC) consultation. These themes provide valuable insights and guidance for developing and improving hospital-based palliative care programs. Most of the themes highlighted the unique nature of the IPC consultation and had a positive tone. Effective communication and the information provided by the IPC team played a significant role in helping family members make care decisions. The opportunity for unhurried discussions and the availability of the palliative care team for further questions were important qualities appreciated by patients.

Furthermore, family members perceived a distinct shift in the clinical approach, transitioning from a traditional disease-centered model to a holistic approach that emphasizes quality of life and comfort. Participants in this study also observed the positive effects of the IPC team's well-documented success in pain management.

The acceptability of Palliative Care (PC) teams to patients and families is essential for delivering high-quality services. Family members identified that one area for improvement in the PC consultation is the consistency of the information provided. Conflicting reports between primary care physicians or specialists and the PC team were perceived as a weakness and negatively impacted the team's credibility. These discrepancies may result from variations in prognosis among providers or their efforts to maintain hope for the patient and family. To enhance the family's experience, it is crucial to increase efforts to involve referring physicians in the consultation process or to establish good collaborations with them.

This study highlighted that family members' readiness to attend the family meeting and receive comprehensive information about the patient's health and disease trajectory was a significant finding. While previous research has noted that some patients may feel overwhelmed by excessive information about their condition, the concept of *"readiness*" has not been extensively explored in the literature. Evaluating the knowledge and readiness of patients and families to receive information is crucial during family meetings. Failure to assess readiness for discussing end-of-life issues has been identified as a common clinician behavior that can increase suffering among patients and caregivers. It is recommended that physicians employ techniques such as stage of change theory or motivational interviewing to assist families in reaching a state of readiness for these discussions.

Additionally, the quality of the experience was negatively affected when family members felt rushed

into scheduling, lacked an understanding of the meeting's purpose, or had insufficient time to prepare. These concerns have been documented in previous studies. Another frequent concern among participants was the perception that palliative care was introduced too late in the illness, which limited its effectiveness in goal setting and decision-making.

Addressing these issues by improving the timing, preparation, and understanding of the family meeting is essential to enhancing the overall quality of the experience. Further research is needed to explore whether similar readiness dynamics are present for family members and to understand how emotional numbness might affect the effectiveness of end-of-life discussions.

Author Contribution Statement

FF: Conceptualization, methodology, investigation, data curation, writing- original draft. RI: Data collection, formal analysis, writing- review and editing. EHO: Methodology, validation, writing- review and editing. SAS: Investigation, resources, supervision. JY: Data collection, formal analysis. MA: Supervision, project administration. MF: Writing- review and editing, validation. All authors read and approved the final manuscript.

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Ethical Approval

This study was approved by the Institutional Review Board (IRB) at King Hussein Cancer Center (Approval Number: [Insert if available]). All procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki Declaration and its later amendments.

Availability of Data

The datasets generated and analyzed during the current study are not publicly available due to the sensitive nature of the data and to protect participant confidentiality, but are available from the corresponding author on reasonable request.

Study Registration

This study was not registered in any clinical trial registry as it is a qualitative observational study and does not involve any intervention.

Conflict of Interest

On behalf of all authors, the corresponding author declares that there are no competing interests.

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