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Nurses' perceptions of compassionate care in pediatric oncology: a qualitative interview study

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Abstract

Background Compassion is a crucial aspect in the management of pediatric oncology patients as it has the potential to enhance nurse satisfaction levels, thereby further enhancing the quality and safety of the care they deliver. This study aimed to investigate nurses' understanding and experience of compassionate care when working in pediatric oncology departments.

Methods This research utilized a qualitative descriptive design. Content analysis was used to make sense of data collected via individual and semi-structured interviews conducted with nurses ($n = 32$) working in pediatric oncology departments.

Results Nurses' understanding of compassionate care for children with cancer was organized into two categories: Humanistic compassionate care and compassionate end-of-life care. The humanistic compassionate care category comprised of three subcategories: (1) empathy, (2) altruism, and (3) respect for the cultural values and beliefs of the family. The compassionate end-of-life care category comprised of two subcategories: (1) facilitating parents' presence at the child's bedside and (2) creating suitable conditions for accepting the death of a child.

Conclusion Compassionate care for children with cancer is marked by a strong emphasis on humanistic, cultural, and end-of-life considerations. Our findings further emphasize the paramount importance of taking families' presence, wishes and beliefs into consideration within this context.

Keywords Compassionate care, Pediatric oncology, Nursing care, Qualitative research

Background

Cancer is one of the most prevalent causes of death in pediatric patients, with approximately 12% of affected children not surviving [1]. The clinical incidence rate of cancer in children in the United States is 178.3 per 1 million children, with leukemia being the most common type, accounting for 46.6% of all childhood cancers [2]. In Iran, the mortality rate for pediatric cancers is reported to be 69.5% [3], and patients in pediatric oncology departments frequently experience high rates of clinical deterioration, necessitating specialized and long-term care [4]. A child's diagnosis with cancer not only affects their own

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life but also poses challenges for their entire family [5]. A child with cancer requires long-term engagement with healthcare services [6]. In Iran, the occurrence of childhood cancer exacerbates the adverse effects on the psychological well-being of extended family members, and families may experience a sense of impairment in their ability to manage the situation [7].

Compassion is indispensable in the delivery of care to pediatric cancer patients [8], and is deemed essential in the delivery of excellence in care by healthcare providers [9]. Consequently, compassion has become a topic of increasing interest within healthcare in recent years [10]. Compassion has evolved to become a central value in clinical practices [11] and an ethical facet of nurses' performance [9]. Indeed, compassion has been defined as a central concept and necessary feature of safe, high quality healthcare and is as important to patients' and families' overall healthcare experience as the health interventions and treatments they receive [12, 13]. Specifically, compassion in pediatric healthcare has been conceptualized as an attitude, feeling, trait, or state that arises in witnessing the suffering of another [12]. Contrariwise, a lack of compassion is associated with increased adverse medical events, diminished patient resilience, and increased patient complaints and malpractice suits [13]. The provision of compassionate care in pediatric settings leads to improved well-being for children [14], and is therefore viewed as one of the fundamental elements of competent care [15].

Numerous studies on compassion in pediatric care have been conducted internationally. A scoping review has also highlighted how several factors are related to compassion in pediatric healthcare, including continuity of care, communication, and the coordination of care [12]. Spanish caregivers for children with life-threatening diseases perceive their role as being the alleviators of their stress through the giving of compassionate care [16]. Similarly, in Canada, a study that engaged pediatric oncology healthcare providers, children with cancer, and their parents underscored that compassion serves as the cornerstone of caring for these children. Compassion has also been identified as a beneficent response that seeks to address the suffering and needs of a person and their family through relational understanding and shared humanity [13]. However, providing compassionate care to children poses challenges for nurses. A review of the literature highlighted how the frequent and lengthy hospitalizations of children living with chronic and complex medical needs may lead to increased compassion fatigue in nurses [17]. Compassion fatigue has been defined as an acute loss of emotional and physical energy toward the self and work, with a hindered ability to deliver compassionate care for patients experiencing suffering [18]. The authors of one study conducted in Greece reported

that almost two thirds of pediatric intensive care nurses were at medium-risk of compassion fatigue [19]. Similar results have also been reported for nurses experiencing compassion fatigue in the United States [18, 20].

Evidently, the very act of providing compassionate care, which is so central to the nursing profession, can also contribute to the development of compassion fatigue. This creates a difficult paradox for nurses who are dedicated to their patients but also need to protect their own well-being. Understanding compassionate care in the context of compassion fatigue is essential because it may reveal how the very act of providing compassionate care can make nurses susceptible to compassion fatigue and thus inform future prevention strategies. Compassion fatigue is frequently linked to absenteeism, reduced work performance, low job satisfaction, and the departure of pediatric healthcare providers from their positions [20]. Given these outcomes, it is crucial to proactively prevent compassion fatigue in pediatric healthcare providers. Nevertheless, there is limited knowledge regarding nurses' perception of compassion, particularly in the context of pediatric oncology nursing in Iran. Considering the above, there presents an opportunity to explore the perspectives of nurses working in pediatric oncology departments in relation to how their comprehension of compassionate care may have been shaped.

Aim

This study aimed to explore nurses' understanding and experience of compassionate care when working in pediatric oncology departments.

Methods

Research design

This study used a qualitative design, which was considered most appropriate for comprehensively exploring understudied concepts from first-hand experiences. The qualitative research design lies within the naturalistic approach and allows for a rich explanation of healthcare workers' experiences using their own language and perspectives [21, 22].

Settings and sample

The research was carried out at the oncology department of the Ali Bin Abitalib Education Hospital in Zahedan, Iran, where children with cancer receive treatment and care. This pediatric oncology department is located in an urban area and accommodates 18–22 patients. Participants were selected via purposive sampling, and were eligible for inclusion if they had at least one year of experience in caring for children with cancer. A diverse group of nurses was sought, considering variables such as age, gender, educational level, nursing experience, and length of experience in caring for children with cancer.

Data collection

After obtaining ethical approval, the first and second authors coordinated with lead nurses within the department, who acted as gatekeepers to eligible participants and made introductions accordingly. Prior to any interviews taking place, eligible participants were invited to read information regarding the interview process and the aims of the research. Those who then volunteered to be interviewed were invited to give their informed consent to participation and were assured that all of their information would be kept confidential by the research team. They were also informed that they could withdraw from the study at any time without giving reason.

Nurses were interviewed in the interview room situated within the pediatric oncology department. During the interviews, only the interviewer and the nurse participant were present. Interviews were semi-structured and conducted individually during the last three months of 2022. Each interview lasted between 40 and 50 min and was conducted in Persian. Each nurse was interviewed once. This resulted in a total of 32 interviews, conducted whilst the participants were not on duty. The first author, a female nurse, and an experienced qualitative researcher conducted interviews. The interview guide was developed by the research team and based upon findings from existing literature. During the interviews, nurses were asked two primary questions: “How would you, as a nurse, define compassion in care?” and “Can you share your experiences of providing compassionate care to children with cancer?” Additionally, follow-up questions and prompts like “Please elaborate on this,” “What do you mean by...?” and “Could you provide an example?” were used to facilitate in-depth responses from the participants. Each interview was audio recorded and transcribed verbatim into text in preparation for manual data analysis (A sample of interview *transcript* in the supplementary file 1). Recruitment occurred alongside data collection, until data saturation was achieved, and no new themes were generated from the data.

Data analysis

Data collection and analysis were conducted simultaneously. Data analysis was performed by the first and second authors. Content analysis was used to make sense of the data collected [23], whereby transcripts were reviewed multiple times to gain a broad overview and understanding of the data, prior to extraction of units of meaning. Semantic units of meaning were subsequently identified from the data. Codes were then generated from these semantic units, and then organized into subcategories based on their similarities and differences. Finally, subcategories were grouped together to form larger categories in line with the content analysis approach [23].

Trustworthiness

Four criteria, namely credibility, confirmability, dependability, and transferability, were employed to bolster the rigor of this study [24]. To determine the credibility of the data, ongoing scrutiny of the data was being performed. The research team's insights were sought throughout the data collection and analysis processes through academic discussion. The interview transcripts and findings were also returned to all nurse participants who were invited to make comments and corrections as appropriate for member checking. To enhance confirmability, we used triangulation whereby the team examined coding accuracy and reliability throughout in partnership with each other. To determine the dependability of the data, all research activities were meticulously documented and reported to best reflect the research team's analysis with accuracy. To enhance transferability, we used purposeful sampling whereby in choosing individuals who were likely to provide rich and relevant data, we aimed to increase the chances that our findings would resonate with others in similar situations.

Results

A total of 32 nurses participated in this study, with ages ranging from 25 to 49 years. The majority of participants ($n=18$) were cisgender women. Most of the nurses held a bachelor's degree ($n=24$), while the rest had a master's degree. Their nursing experience ranged from 5 to 17 years, and their experience in caring for children with cancer ranged from 2 to 14 years. All of the participants were working full-time in hospital settings at the time of data collection.

Findings from our data analysis generated two major categories with regards to the delivery of compassionate care for children with cancer: (1) Humanistic compassionate care and (2) Compassionate end-of-life care. The humanistic compassionate care category consisted of subcategories ($n=3$), namely, (1) empathy, (2) altruism, and (3) respect for the cultural values and beliefs of the family. The compassionate end-of-life care category also encompassed subcategories ($n=2$), namely (1) facilitating the presence of parents at the child's bedside and (2) creating suitable conditions for accepting the death of a child. These categories and subcategories are presented below with participant quotes used to highlight overall sentiments captured within the data.

Category one: humanistic compassionate care

According to the nurses in this sample, compassionate care for children with cancer is infused with humanistic elements, which include empathy, altruism, and a deep respect for the cultural values and beliefs of the family.

Subcategory: empathy

According to the nurses interviewed, compassionate care for a child involves being empathetic. The nurses described an empathic approach as one involving being present at the child's side, offering companionship, accepting the child unconditionally, and providing gentle, nurturing care. One of the participants describes this summarily as the nurse becoming like a 'protective umbrella'

"It is crucial to actively listen to children with cancer because they experience considerable pain. Active listening involves paying close attention to their needs and being a supportive, attentive listener. This is achieved by staying by their side, ensuring they know we are there for them, and addressing their requirements. When we adopt this perspective towards children, it signifies our acceptance of them. Embracing the child with acceptance allows us to provide compassionate care, and in such a role, the nurse becomes a comforting presence, akin to a protective umbrella for the child with cancer." (P6).

Nurses perceived viewing the child with cancer as their own child as essential in delivering compassionate care. In taking this approach, nurses are better able to connect of the child in the present moment, and are thus better able to alleviate their suffering, empathize, and cast a comforting presence. Indeed, participants described this as follows:

"When there is compassion in the care of children with cancer, I believe their care is executed exceptionally well, as it allows us to connect with the child in the present moment. This quality in caring for a child with cancer alleviates their suffering and enables the nurse to serve as a protective presence. This type of care ultimately makes the nurse act as a shadow in the care of a child with cancer." (P14).

"When I care for these children, I approach it as if my own child or one of my close relatives were hospitalized here. The presence of cancer makes no difference." (P18).

Subcategory: altruism

Participants described how compassionate care for a child with cancer is inconceivable without altruism. Such altruism involves going beyond one's professional duties and performing acts for the child's benefit, even without their explicit request. The following two quotes highlight

this sentiment of altruism, and describe specific incidents where this has occurred in practice.

"The nurse in this context undertakes tasks that the child hasn't specifically asked for. She goes above and beyond her professional duties, acting out of her innate humanity. Without this altruistic dimension, compassionate care would lose its meaning." (P3).

"Not too long ago, a colleague of mine bought a doll for one of the children who was in a financially difficult situation. Another colleague purchased a cake to celebrate one of the children's birthdays, and we organized a small party within the department. These moments bring immense joy to the children." (P19).

Subcategory: respecting the cultural values and beliefs of the family

Interviewees outlined how it is of paramount importance to consider and respect the cultural values and beliefs of the families of children with cancer in the context of compassionate care. Where families hold certain beliefs and values that are integral to the patient's healing process, nurses acknowledge and honor these in their compassionate care for children with cancer. Specific incidents of this are described by participants in the quotes below.

"At times, we encounter children whose parents tie a green cloth around the child's wrist, which signifies healing. I respect this value and belief held by the family, rooted in our culture, as it is perceived to contribute to the child's recovery. Even during procedures like changing the angiocyte, I make sure not to discard the cloth." (P10).

"Once, during my shift, the grandfather of a child who had recently returned from a Hajj trip brought Zamzam water for the child, having heard of his grandson's cancer. He believed that the blessed water would aid in the child's recovery. This reflects a cultural value within our society, which holds great significance for the family. We make every effort to respect and accommodate these beliefs." (P24).

The results of this category indicate that, according to the perspective of nurses in pediatric oncology, concepts such as empathy, altruism, and respecting the cultural values and beliefs of the family are essential for delivering humanistic compassionate care.

Category two: compassionate end-of-life care

In the context of providing compassionate care during the end-of-life phase for children with cancer, nurses facilitated the presence of parents at the child's bedside and created suitable conditions for accepting the death of a child.

Subcategory: facilitating the presence of parents at the child's bedside

The nurses were well aware that some children with cancer ultimately do not recover, and that their journey ultimately ends with their death. As such, their focus in providing compassionate care was centered on creating opportunities for increased interaction between parents and children. The two quotes presented below highlight how it was particularly important to keep children together with their families during this time as part of the compassionate care they received.

"We reduced visitation restrictions and sought permission from the supervisor to allow parents to visit their children regularly during the end-of-life phase, even when there were no scheduled visiting hours. This mutual visitation need holds significant importance for both the child and the parents." (P30).

"I make an effort to avoid separating mothers from their children during the final moments of a child's life, even if hospital laws might not permit it. This is because it fulfills the parents' need during this critical time, and I consider it one of the essential components of compassionate care." (P26).

Subcategory: creating suitable conditions for accepting the death of a child

Nurses made deliberate efforts to compassionately prepare the families of the children to confront and accept death. They firmly believed that it was the right of parents to be informed about their child's imminent death, and they provided the parents with the necessary information about their child's condition as part of compassionate care they delivered.

"It is the right of parents to be informed about their child's condition and impending death. We make it a point to keep parents informed about this, including providing them with an estimate of the expected time of their child's passing." (P15).

"I communicated with the ailing mother and conveyed the unfortunate news that her child's illness was advancing, and despite all efforts, her child had passed away due to the progression of the illness." (P22).

Offering condolences to the family and creating the conditions for them to bid their final farewells to the child, while also assisting in their preparation to navigate the mourning process, was another vital role played by the nurses in delivering compassionate care. Two participants describe how they did this below.

"When a child passes away, it's imperative for me to extend my condolences to the grieving family. Such expressions of sympathy from the nurse, when coupled with compassion, help prepare the family for a heartfelt farewell to their departed child." (P20).

"I believe that by allowing parents to say their final goodbyes to their child before the body is taken to the morgue, we can assist them in coping more effectively with the grieving process." (P9).

According to the findings of this category, nurses in pediatric oncology prioritize the facilitation of parental presence at the child's bedside and the creation of suitable conditions for accepting the child's death as part of providing compassionate end-of-life care.

Discussion

In the present study, we investigated nurses' comprehension and experience of compassionate care for children with cancer. Findings from our data analysis resulted in two categories with regards to the delivery of compassionate care for children with cancer: (1) Humanistic compassionate care and (2) Compassionate end-of-life care. According to the nurses interviewed, compassionate care is inextricably intertwined with the humane and empathetic aspects of end-of-life care for these young patients. Ultimately, nurses highlighted that compassionate care for children with cancer encompasses empathy, altruism, and respect for the cultural values and beliefs of the family.

Nurse participants expressed how establishing empathy with children with cancer entails being present with the patient, connecting with them, and wholeheartedly accepting them. This also involves actively listening to the patient and truly seeing them. A study conducted in Canada similarly found that compassionate care is a multi-dimensional concept at its core, with empathy being a fundamental aspect [25]. Understanding the perspectives

of others, effective communication, active listening, and genuine attentiveness have also been identified as integral components of compassionate care in existing studies [26]. The findings derived from the present study suggest that compassion is ingrained in the nurses' approach to care, driven by a desire to alleviate the suffering of children with cancer. This finding has also been identified in a previous study exploring nurses' perception of compassion [27]. Participants also used metaphors such as a 'protective umbrella' and 'shadow nurse' to illustrate their empathetic approach in caring for these children. Such risks call for both preventative action and risk reduction. These similar findings suggest confirmatory perceptions in nursing with regards to the delivery of compassionate care, and thus may usefully contribute to frameworks of compassion in nursing care, along with support for the nurses providing such care more widely.

Our findings demonstrate how compassionate care for children with cancer is fundamentally rooted in altruism. Participants emphasized that going beyond their professional duties, such as organizing a birthday celebration for a child without any specific request, holds significant importance in compassionate care. These actions, they noted, stem from a sense of shared humanity. Similarly, in Iran research has highlighted how nurses' altruism in their interactions with cancer patients ultimately leads to the establishment of effective communication with the patient and the delivery of compassionate care [28]. A concept analysis on compassion in healthcare similarly identified altruism as one of the attributes of compassion [29]. The altruism identified in our findings may also contribute to nurses' compassion fatigue as they continue to find it necessary to go "above and beyond" their duties in order to provide the compassionate nursing care they are dedicated to. This uncovers a paradox wherein compassionate nursing care is considered to enhance the safety and quality of care, and yet has the potential to diminish the wellbeing and safety of nursing staff.

Furthermore, findings here underscore the importance of respecting the cultural values and beliefs of families in the context of compassionate care for children with cancer. Evidence from Iran similarly demonstrates how compassionate care is delivered by paying attention to the beliefs and values of patients and showing concern for family members [30]. As examples, nurses participating in our study demonstrated respect for practices such as tying a green cloth around a child's hand or providing Zamzam water, both of which hold cultural and healing significance within Iranian culture. These practices are rooted in the beliefs and values of the people and are perceived to possess healing properties. This illustrates how compassionate care for children with cancer is indeed influenced by cultural beliefs and values, particularly in the context of Iran. Consequently, it becomes necessary

to acknowledge the role of culture in the provision of culturally safe and compassionate care for children with cancer. Furthermore, these findings demonstrate how this form of care not only centers on the child but extends to encompass their family as well.

In the context of providing compassionate care to children with cancer at the end of their lives, our findings demonstrate that nurses actively facilitate the presence of parents at the child's bedside and enable important end-of-life acts in a considered and compassionate way. For example, the nurses were able to provide suitable conditions for the family to accept the child's death more effectively. Research conducted with care providers in Brazil similarly highlighted the essential need for such compassionate care for children at the end of life [31]. In our study, nurses also worked to ensure that parents could remain by their children's side consistently, even by lifting restrictions on visitation rules. Despite the unique conditions and regulations governing parental presence on hospital wards, nurses made efforts to enable parents to be with their children continuously. Moreover, our participants provided families with information about the child's impending death and helped them come to terms with this reality. This enabled parents to say goodbye to their child and have support throughout the grieving process. Likewise, evidence from elsewhere in Iran demonstrates that in end-of-life care for children with cancer, nurses also informed the families about the progression of the disease [32]. These findings underscore several acts of compassion and their critical importance in the implementation of compassionate care for children with cancer at the end of their life.

The current study represents the first qualitative research endeavor focused on the care provided by Iranian nurses especially in the context of compassionate care for children with cancer. Our findings highlight unique insights into compassionate care in this context in Iran. Our findings demonstrate that from the perspective of nurses, compassionate care for children with cancer is related to concepts such as empathy, altruism, respect for family values and cultural beliefs, and the needs of the family at the end-of-life of a child with cancer.

Limitations

Due to the qualitative nature of this research, generalizability of the findings to diverse contexts and cultural milieus is not feasible. Yet we have sought to enhance the credibility, dependability, confirmability, transferability, and rigor of this research throughout.

Implications for future research

As the findings indicated that families are also important to nurses in the compassionate care of children with cancer, future research could usefully encompass a thorough

examination of compassionate care in partnership with families to unearth additional intricate facets which may be apparent in this context. Considering that the instruments for measuring compassionate care in pediatric oncology are limited from the point of view of nurses, it is suggested that the results of this study be used to design instruments in this field.

Conclusion

We conducted the first content analysis of nurses' understanding of compassionate care for children with cancer in Iran. Compassionate care for children with cancer in this context is marked by a strong emphasis on humanistic, cultural, and end-of-life considerations. Our findings further emphasize the paramount importance of taking families' presence, wishes and beliefs into consideration within this context. The exploration of nurses' perceptions revealed that compassionate care in pediatric oncology is a multidimensional concept that is particularly influenced by cultural factors. Nursing managers can identify and recruit compassionate nurses to deliver high-quality care by highlighting the various dimensions of the concept of compassionate care within the specific context of pediatric oncology, as identified in this study.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12913-024-11661-1>.

Supplementary Material 1.

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Authors' contributions

Study design: MG, MMH. Data collection: MG, MMH. Data analysis: MG, MMH. Study supervision: MG, MMH, SP. Manuscript writing: MG, MMH, SP. All authors have read and approved the final manuscript.

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Availability of data and materials

The datasets generated and analysed during the current study are not publicly available due to the confidentiality and the traceability of the qualitative data but are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

All methods were performed in accordance with the relevant guidelines and regulations. In order to comply with ethical considerations, permission to conduct the research was obtained from the ethics committee of Zahedan University of Medical Sciences (IR.ZAUMS.REC.1401.122). Potential eligible participants were given information about the study and its objectives. They were then invited to offer their written informed consent, which was obtained prior to their entry the study and the recording of interviews.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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