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Professional Caregivers' Challenges and Strategies in Communicating with Parents in Pediatric Oncology

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Abstract

Effective communication between professional caregivers and parents is crucial in pediatric oncology, where families face emotionally and cognitively demanding situations. This study explores caregivers' perceptions of providing information to parents of children diagnosed with cancer, focusing on communication strategies, challenges, and ethical considerations. Using qualitative and/or quantitative methods, the research examines how caregivers balance delivering clear, accurate medical information while addressing parental emotions and concerns. Findings highlight the importance of tailored communication approaches, interdisciplinary collaboration, and the need for continuous training to enhance information-sharing practices. Improving these interactions can strengthen trust, support decision-making, and improve overall family-centered care in pediatric oncology.

Keywords: ***Pediatric oncology, professional caregivers, parental communication, information sharing, family-centered care, healthcare communication, ethical considerations, support strategies.***

1.Introduction

A child's cancer diagnosis makes parenting one of the toughest and most painful situations a family must ever face. Diagnosis hits the family by surprise to produce deep emotional reactions that force them into a novel complicated medical system changes their family life. The journey features considerable uncertainty because parents must face tough choices concerning available therapies and probable side effects with current and future disease expectations (Björk, Wiebe, & Hallström, 2005; McGrath, 2002; Woodgate & Degner, 2002). People undergoing this experience often experience overwhelming pressure which causes psychosocial distress together with anxiety alongside the inability to handle or recall essential medical data (Pai et al., 2007).

Pediatric oncology care relies heavily on delivering prompt and correct information to cancer-stricken children's parents because it constitutes an essential requirement in treating these cases. Parents who have access to properly organized information about their child's condition achieve better results in treatment decision-making and symptomatic management as well as remaining in control during uncertain times (Björk et al., 2005; Kerr et al., 2007; Ljungman et al., 2003; von Essen, Enskär, & Skolin, 2001). Even though healthcare professionals agree about the critical role of communication in parent education all healthcare facilities deliver information to parents in different ways. Parents experience two divergent issues when dealing with extensive medical information since some feel overwhelmed while others cannot get sufficient answers from healthcare providers (McGrath, Kail-Buckley, & Philips, 2007). Healthcare professionals experience major difficulties when seeking appropriate information delivery methods which address individual family priorities and requirements(1).

Björk et al. (2005) have described parental experiences of child cancer diagnosis as a "broken life world" that shatters their sense of reality leading them to understand and relate with frightening medical circumstances. When faced with such circumstances parents start "striving to survive" by employing medical information together with every other available resource to regain stability while reducing their overwhelming experience of chaos. The method used to furnish information plays an essential role in determining how effectively parents grasp the information. The retention of information during times of stress becomes hindered per research findings so parents have trouble comprehending medical terminology immediately after diagnostic disclosure (Jedlicka-Köhler, Götz, & Eichler, 1996). The effectiveness of parental understanding and care depends on caregivers to decide the appropriate content along with the most optimal timing and delivery methods of medical information(2).

Professional caregivers carry out many duties in their roles in this specific context. Professional caregivers surpass medical fact transmission by requiring emotional support combined with clarity-building techniques alongside trust-building practices. The process of parent education within pediatric oncology requires ongoing attention as well as compassionate conduct and flexible communication techniques and adaptable behavioral approaches. The medical field lacks a standardized definition of information for such circumstances. Research studies differ about the classification of information delivery as a component of social support (Stoltz, Andersson, & Willman, 2007) or patient education (Piredda, 2004) and patient empowerment (Leino-Kilpi, Mäenpää, & Katajisto, 1999). Information in this study extends broadly to include every comment parents receive about their child's illness together with their treatment and self-care mastery for home-based disease management(3).

The swift learning challenge regarding information-sharing intensifies between parents and healthcare providers. According to McGrath et al. (2007) parents caring for children diagnosed with acute lymphoblastic leukemia need to learn medical terms and staff protocols within limited time. Some parents actively search for complete information but alternative parents develop information overload which leads them to prefer controlled information amounts. Due to diverse parental information preferences health professionals should adopt an approach that provides both individual customization and flexibility in their communication methods. The constant patient care activities by nurses make them the leading source of data for parents. Hospital caregivers identify how parents rely more often on Internet resources to support their hospital information collection (McGrath et al., 2007). Although online resources provide valuable information parents should be cautious because they often stumble upon inaccurate and misleading content which makes their anxiety worse.

Published research shows that pediatric oncology professionals need to improve their communication methods because parents consistently report unsatisfactory information experiences. The Pöder & von Essen (2009) research discovered that parents evaluated information delivered by physicians and nurses with lower satisfaction ratings than other aspects of healthcare in Sweden(4). The research demonstrates that specific healthcare professionals place emphasis on exclusive types of information. The nursing profession delivers information about topics including symptom management and self-care as well as chemotherapy protocols yet physicians tend toward emphasizing medical diagnostics and treatment options (Kelly & Porock, 2005). The need for different types of information regarding cancer care changes during treatment according to caregivers who have observed parental development (Bradlyn et al., 2004). Previous studies analyzed parental perspectives about information-sharing but an important knowledge gap remains in exploring how professional caregivers conduct information delivery in their critical care practice. Professional caregivers lack clarity regarding their methods of selecting appropriate information for parents and identifying parental readiness for information and the strategies they employ to enhance communication effectiveness. The research addresses this literature deficiency by evaluating caregiver professionals about their practices when sharing information with parents in pediatric oncology care. This study investigates the communication challenges to create better strategies which enhance care for caregivers and their patients.

2. Methods

A qualitative descriptive research approach was used to gain professional caregivers' perspectives about their experience delivering information to cancer-stricken children's parents. The research subject along with its need for subtle caregiver insights led researchers to decide on qualitative methodology as the most suitable research design. The chosen methodology enables researchers to deeply analyze participant perspectives by studying how subjects understand their experiences instead of forcing them into predetermined boxes.

Staff from a Swedish pediatric oncology ward participate in providing information to parents who care for children experiencing illness. The investigation served as part of a larger initiative to create an intervention for enhancing communication between caregivers and parents. The overarching research initiative consisted of parent interviews alongside direct observational assessments of clinical information exchanges in addition to the caregiver-centered investigation. The general study used diverse methods to understand all dimensions related to pediatric oncology communication through a combination of various viewpoints from different sources(5).

Participants

The research team conducted participant selections from the pediatric oncology ward staff where they obtained representatives from various healthcare professions to study diverse viewpoints. The lead researcher explained the research study to all ward-based professional caregivers who numbered about thirty. Twenty professional caregivers joined voluntarily after examining the interview session availability which was posted on the hospital ward

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announcement board. The research included 11 university-educated registered nurses along with 2 pediatric enrolled nurses holding high school diplomas and specialized training and 6 healthcare staff workers from physiotherapist to social worker to child life specialist roles and one physician.

Each participant belonged to a different professional category and possessed either beginner or seasoned healthcare experience within distinct demographic groups(6). The subject sample underwent age evaluation which revealed 48 years as the median while participants varied between 27 to 64 years. The nursing practitioners had between 2 and 43 years of healthcare experience while the median period was 19.5 years. Participants in pediatric oncology practice worked for 2 to 39 years reaching an average length of service in 8 years. The study incorporated multiple professional experiences by recruiting both healthcare field veterans as well as its newcomers. Male participants formed a minority of two while the majority of participants were female since pediatric nursing and caregiving professions tend to have such gender distributions.

The research study received completion from twenty caregivers even though three selected participants ultimately failed to join interview sessions because of their demanding workload responsibilities on the ward. Pediatric oncology work demands a high level of commitment because healthcare duties typically exceed available research involvement time requirements.

Focus Group Interviews

Four focus group interviews served as the main data collection method to obtain detailed descriptions from caregivers concerning their experiences. Focus groups served as the main data collection approach because participants could engage in interactive exchanges which allowed them to develop and question or refine their understandings with the assistance of fellow participants. The group process during focus groups enables participants to both analyze common experiences with their peers while creating group-level understanding about the topic.

The hospital provided private conference rooms for the sessions which brought together groups of 3 to 7 participants in order to maintain confidentiality and disrupt the proceedings(7). Each interview session persisted for 76 through 85 minutes. The lead researcher (AR) functioned as moderator to direct discussions although the second researcher (UHG) observed and made detailed notes as well as mind maps which captured essential discussion points. The dual researcher approach served to provide full documentation of recorded sessions while providing additional confirmation for analysis results.

The investigators used semi-structured interviews as a discussion framework to maintain both topic flexibility and essential discussion points. The study participants answered three general open-ended survey questions to provide their responses.

- Please elaborate on an occasion when conveying information to parents led to positive results.
- Please share a case when sharing information to parents generated poor outcomes.
- What would be the perfect method for sharing information according to your perspective?

The designed questions asked caregivers to recall personal scenarios instead of requesting theoretical thoughts to obtain genuine and thorough information. The moderator employed follow-up questions for better understanding of participant responses during the interview. The interviewer posed questions like “What made this situation succeed or fail?” and “Has the group noticed related situations before?” to participants. Through this research method researchers identified how caregivers make decisions while learning about what influences their behaviors interacting with parents.

For data accuracy purposes every interview session received participant approval for recording then the researchers transcribed the audio data in its original format(8). The researchers checked the mind maps created throughout discussions with participants once the interview sessions concluded. The final step involved caregivers confirming the information collected as well as providing explanations and new information that they believed was inadequately covered during the discussion.

Qualitative Content Analysis

A systematic evaluation technique called qualitative content analysis determined themes and patterns in the recorded interview transcripts. Content analysis proves suitable for studying communication processes since it helps researchers identify both open and hidden meanings embedded in their data. The research methodology targets commonalities and variations between interview responses from participants to determine their diverse perspectives on information sharing (Graneheim & Lundman, 2004; Krippendorff, 2004).

Multiple readings of the transcribed interviews laid the foundation for achieving complete understanding of the content during the analytical procedure. The researchers split the interview transcript into small meaning units which contained specific data points relating to their study's core subject. Researchers condensed the meaning units into shorter statements without altering the core meaning and each statement received a code to support systematic analysis.

The researchers applied initial coding to the data before categorizing the developed codes through shared features. The research group conducted constant feedback sessions between the gathered data and rising themes to develop categories which accurately depicted caregivers' perspectives. The research team ultimately derived two major themes from the research categories.

Caregivers effectively customize both quantity and complexity of communicated information according to each parent's personal situation this is known as matching information to needs.

The research analyzed a disorganized system as examined the effects of imperfect instructions and inconsistent messaging and logistical problems that hinder connection among stakeholders.

The analysis team returned to original transcript data and mind maps multiple times to check findings and maintain consistency. All researchers discussed any points that differed in their understanding until they agreed upon a unified interpretation.

Ethical Considerations

The qualitative healthcare study honored all ethical standards for research in medical facilities. Data collection began only after the Regional Ethical Review Board in Umeå granted approval through their document with identification Dnr 08029M. The researchers adopted specific protection measures because the study topic involved sensitive content. The researchers provided both written and oral information about research goals together with procedures and ethical protocols to all participating caregivers who then signed consent forms before commencement. Subjects received three important disclosures regarding participation: including voluntary status, right to discontinue at any moment freely and assured confidentiality of their answers. All participants provided their written agreement to participate before starting the study(9).

All personal identifiers were deleted from transcripts before data storage in secure facilities as part of identity protection measures. Since discussing emotionally difficult subjects like parent-child communication issues potentially caused distress for participants the research team closely monitored for signs of discomfort and provided participants the chance to stop participating at any time.

The study sought to deeply understand caregivers' perspectives about informing parents of oncological matters for pediatric patients through a combination of ethical steadfastness and qualitative research strength along with systematic analysis.

3. Aligning the Information with the Needs of the Parents

Information sharing to parents demands professional judgment because caregivers need to supply necessary parent-centric information without subjecting them to intense or distressing knowledge. The process of finding the optimal level of information proved challenging since parents' information needs varied widely due to their emotional state together with their current medical awareness as well as the point in their child's treatment plan.

Providing Too Little Information

The most crucial concern expressed by caregivers involved parents receiving inadequate medical details. Parents sometimes received insufficient information about their child's healthcare because some caregivers falsely believed them to be knowledgeable enough. Medical staff provided brief explanations to parents who previously experienced cancer and relapses in their children. Caregivers providing information to healthcare professionals showed less clarification when they perceived these parents had adequate background awareness. Caregivers admitted that their presumptions about family knowledge turned out to be incorrect which resulted in some parents from these groups feeling uninformed about their children's cancer despite past encounters and professional experience.

Cultural backgrounds and language differences between healthcare providers and their patients affected how much information reached the patients. The preferences for communication remained unclear among families with diverse cultural backgrounds causing caregivers to provide reduced amounts of information. Professional interpreter services failed to provide support for informal and spontaneous conversations which limited opportunities for effective communication because of language barriers(10). The presence of one parent at the hospital more often than the other parent at home became a risk factor because the separated or divorced non-hospital parent received limited information according to caregivers.

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Caregivers identified that parents compensated for insufficient official information by researching on the internet. The caregivers stated their apprehension about online information credibility because parents often found incorrect or panic-inducing material which intensified their anxiety instead of providing relief. It became challenging for caregivers to offer support and rectify wrong information because some parents intentionally kept their internet activities hidden from their guardians.

Compassionate caregivers should present the right level of information to parents

Caregivers felt they gave suitable amounts of information to sick children with good results in most instances. The learning process received intense parental involvement because parents constantly pursued all possibilities of information that would help them gain control of their child's situation. Parents who received care displayed extensive curiosity by frequently seeking thorough explanations about their child's medical condition along with clear explanations.

The caregivers stressed that delivering information needs to be adaptable depending on the situation. The healthcare providers acknowledged that parental comprehension changes depending on how much emotional strain they experience. The caregiver adjusted their information presentation to parental emotional status through ongoing assessment of their readiness and provided more details to receptive parents while simplifying the message to those who appeared overwhelmed. The caregiver explained how one father spent the entire night until 4:30 AM engaged in detailed discussions about his child's condition which showed the deep information need of certain parents.

Making parent involvement essential during the information transmission process represented a successful communication optimization approach(11). Medical staff used two different approaches for question management such as having parents keep written notes or providing support between parents of varying experience levels to help new parents with learning about their child's diagnosis. These communication methods allowed parents to obtain essential information while avoiding feelings of pressure about immediate understanding of the entire material.

Providing Too Much Information

Caregivers noted instances when medical staff gave excessive information which caused their patients to become confused as well as emotionally distressed. Based on the caregiver's account a physician gave an extensive intricate explanation about the child's declining health status to their parents. The mother expressed tears after the meeting because she understood only one important point about being moved to a different hospital facility. The case shows that providing many details in stressful situations causes more problems than benefits for understanding.

The challenge of receiving too much information affected caregivers because it enabled them to stay accessible at all times. Caregivers identified understanding questions from parents as crucial however they faced challenges when parents asked many questions which could have waited for scheduled discussions. The caregivers faced difficulties maintaining optimal efficiency with their other responsibilities because they were always available to parents.

Navigating Through a Vague Structure

The doctors who worked with parents faced many hurdles because of both the task of finding suitable information and because of system-related information dissemination barriers. The information-sharing process faced difficulties because of moving between unstable clinical situations and unclarified team responsibilities and delayed delivery timing and unclear language and underutilized communication tools.

A Disrupted Setting

The caregivers found that information delivery took place in numerous inappropriate and chaotic settings. Urgent discussions occurred within hospital corridors alongside other busy areas causing parents to struggle with listening to important information. A physician chose to share the news about a child having an inoperable tumor while they were both in a stairwell which led both parties to experience unbearable distress that remained difficult to cope with.

Shortages of staff members combined with excess patient caseloads made the problem worse. The healthcare team performed essential explanations in a hurry or delayed essential talks because of extreme patient load in the ward. Parents chose to let the staff operate without interrupts because they believed their heavy workload needed attention(12).

Unclear Responsibilities Within the Team

A key obstacle to successful communication emerged from untreated organizational guidelines about what team members should provide to patients regarding specific types of information. The primary nurses held responsibility

for information coordination yet physicians and other staff members occasionally introduced confusing and insufficient information to patients. The doctor provided a physician update about treatment limitations to the mother without consulting nursing staff causing her to panic along with her confusion.

The caregivers proposed adopting formal debriefing sessions together with checklists to establish consistent team messaging across all members of staff.

Difficult Timing and Unintelligible Information

The caregivers identified that when information reached parents would determine their ability to understand the message. Medical staff became unavailable for post-news follow-ups after making bad news announcements close to the afternoon so parents had to manage their despair on their own overnight. According to caregivers small components of repeated information worked better than supplying extensive complex data sets to parents at one time.

The caregivers confirmed that using medical professional terminology produced difficulties in patient comprehension. Medical professionals were sometimes observed giving complex explanations to parents which challenged their ability to understand essential components of the discussion(13). The strategy of speaking in straightforward language combined with confirmation checks gave caregivers a method to enhance their communication effectiveness.

Underused Tools for Communication

Several educational resources including illustrated booklets together with digital resources and group information sessions existed for caregivers yet they did not maximize their potential for effective use. Caregivers who took part in the study shared the opinion that enhanced implementation of existing resources would allow parents to learn according to their individual pace while accessing important concepts repeatedly.

4. Discussion

This study showed that professional caregivers encounter several obstacles during patient information delivery to parents whose children have cancer. Pediatric oncology communication goes beyond knowledge transfer because it follows a context-dependent method which needs sensitive attention to parental emotions along with comprehension levels and moment selection. Professional caregivers face two main problems when sharing information with cancer parents and providing treatment details due to vague treatment structures in addition to unpredictable parental information demands. The paper establishes links between these results with medical literature from pediatric oncology communication while evaluating their clinical practice implications.

The Balancing Act of Information Provision

The study reveals the precise method patients and caregivers need to provide appropriate information amounts. The preferences of parents show extensive diversity because some parents want complete detail but others find an abundance of information to be unmanageable. Previous research confirms that parents caring for children with cancer need help in learning rapidly because their information needs change over time (McGrath et al., 2007).

The central idea of informational empowerment explains this situation best. Research demonstrates that informed parents build better confidence in medical child management and this increased confidence both reduces their anxiety and helps them make better medical choices (Virtanen et al., 2007). Information delivery done either in excessive quantities or at improper times can result in elevated parental anxiety as well as confusion and a helpless state. Research has already demonstrated what is known as the information paradox where insufficient or excessive information can cause distress (Mack et al., 2006).

Caregivers face one of the most difficult circumstances when they need to help parents who deliberately turn away from learning about the situation. Parents who avoid dealing with reality create barriers by refusing to receive full information updates primarily when the situation turns unfavorable. Caregivers face an ethical challenge since they need to honor their patients' ways of coping yet they must continue providing families with proper information. Studies by Kreicbergs et al. (2004) showed parents who kept away from prognostic discussions later criticized not knowing enough which indicates that nurses should use steady or incremental approaches to deliver tough information.

The internet functions as a substitute information source that creates advantages along with hazards. The caregivers had several worries regarding web-based medical info precision because they feared parents could come across inaccurate data which might cause unnecessary unwanted emotions or misguided optimism. When healthcare professionals provide proper navigation of online resources parents receive benefits from useful supplemental information (Anderson & Klemm, 2008). Research evidence indicates caregivers should lead parents to trustworthy digital platforms instead of discouraging their internet interaction.

The Structural Challenges of Information Delivery

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Research found major system obstacles in healthcare leading to ineffective information transfer between medical staff and patients. These research results correspond to healthcare literature which examines organizational inefficiencies alongside their effect on patient and family satisfaction (Moore & Kordick, 2006).

Healthcare providers face the major challenge of not having uniform procedures to share information. Caregivers recognized primary nurses as the coordinators of patient communication but expressed frustration about inconsistent methods used for providing updates at various times from different healthcare staff. An unstructured information-sharing process generates multiple negative effects for parents who receive inconsistent information from different caregivers while some essential details tend to go missing leading to unclear roles for caregivers within this process. Some hospital units have implemented SBAR (Situation-Background-Assessment-Recommendation) communication protocols to enhance medical communication clarity and consistency according to Kerr et al. (2007). Medical settings that adopt standardized communication systems should reduce these communication problems within pediatric oncology departments.

The delivery of information through certain settings constitutes an additional structural problem within information-sharing processes. The caregivers who participated in this research often faced uncomfortable delivery situations when critical information sharing took place in busy hospital passages and hallways because of rapid deadlines and staff workload demands. The analysis of research shows that the selected environment for bad news disclosure heavily impacts the processing and reception of information by the patient (Fulton, 2008). Hospitals need to create private and quiet spaces for essential conversations between healthcare providers and parents so they possess ample time to understand the provided information.

Timing emerged as a repeated major point throughout the interview process. When physicians were not available after afternoons to answer parental questions caregivers reported that the delivery of complex or distressing information triggered unnecessary anxiety in parents. Research by Sloper (1996) confirmed the effectiveness of sharing information gradually and in a proper timeframe instead of providing complete large amounts of information (Sloper, 1996). Doctors should organize earlier informational meetings and produce written summaries about essential meeting conversations to aid parents' information retention and eliminate their dependence on immediate impromptu exchanges.

Research data showed a lack of appropriate educational resources being used. The caregivers indicated that existing pamphlets together with visual aids along with online modules were obtainable yet they were not properly incorporated into the information dissemination flow. The medical faculty is missing a key point because studies show that combining oral explanations with written materials and visual aids increases patient retention and comprehension of medical content (Wainstein et al., 2006). Creating an organized system to combine parent instruction with educational materials would benefit hospitals by allowing parents to receive both verbal information and independent study resources for improved comprehension.

5.Conclusion and Future work

Professional caregivers must maintain effective communication with parents of children battling cancer because it serves as a critical aspect of excellent pediatric oncology care. This research established how difficult it remains to achieve optimal delivery of information to parents along with suitable timing combined with supportive emotional settings. Professional caregivers need to carefully balance the amount of patient information they share to parents because an overload can result in increased anxiety but under-sharing information leads to confusion and diminished medical decision-making confidence. Healthcare providers should use flexible yet sensitive methods with structured protocols when sharing information because the results show this approach is crucial in situations that require emotional care for families.

The study provides important insights which indicate that healthcare providers need thorough procedures when delivering medical information. When individual caregivers base their parental information assessments on their instinct and practical experience there exists a risk of inconsistent care because institutions have no official guidelines. The care team gives different members to parents conflicting information while certain parents find it challenging to get their most urgent questions answered. Standardized communication protocols with designated personnel who

distribute information before scheduled sessions would improve the continuous exchange of information between caregivers and parents and maintain consistent delivery of vital details.

The physical setting and emotional atmosphere where medical information is delivered strongly affects parent success in processing and storing medical information. Caregivers frequently shared situations where essential information needed to be shared in inadequate locations including hallways or stairwells because of urgent time demands and work-related pressures. The results of this study match earlier studies which show that privacy during communication and limited interruptions and access to supportive health professionals result in better communication success rates. As a primary objective pediatric oncology teams should create low-stress areas with opportunities for caregivers to question and process the information they receive.

Educational resources together with supplemental materials help parents develop deeper comprehension of medical information received. The available booklets along with visual aids and online resources did not achieve their maximum value as demonstrated by caregiver admission. Healthcare facilities and pediatric oncology units must adopt better practices to integrate a variety of educational resources into information-sharing programs. The provision of evidence-based online materials alongside illustrated guides and structured education sessions for groups enables parents to understand information at different speeds which reduces their need to have spontaneous interactions with hospital staff.

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Conflicts of interest

The authors have no conflicts of interest to declare

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