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RESEARCH REFLECTION

Research in pediatric oncology: Engaging parents to strengthen research processes, outcomes and knowledge translation

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ABSTRACT

Childhood cancer is the most common disease-related cause of death in Canadian children aged 0-14 years, with more than 1,000 new diagnoses every year (Canadian Cancer Statistics Advisory Committee, 2019). Treatment for childhood cancers requires complex, intensive, and lengthy regimens, often lasting years. Each new diagnosis marks tremendous upheaval in the lives of the child and their family, and an opportunity for nurses in pediatric oncology to make a difference. However, to best intervene, it is crucial to understand the experiences and needs of parental caregivers who have children in treatment for cancer. Patient Oriented Research is one way to bring together patients, family members, researchers, healthcare providers, and decision-makers to actively collaborate, understand best practices, and create transformational positive change in pediatric oncology.

INTRODUCTION

Childhood cancer is the most common disease-related cause of death in Canadian children aged 0–14 years, with more than 1,000 new diagnoses every year (Canadian Cancer Statistics Advisory Committee, 2019). Treatment for childhood cancers requires complex, intensive, and lengthy regimens, often lasting years. Each new diagnosis marks

tremendous upheaval in the lives of the child and their family, and an opportunity for nurses in pediatric oncology to make a difference. However, to best intervene, nurses in education, practice, and research must understand the experiences and needs of families who have children in treatment for cancer. Because of the intense nature of parental care involved, the length of time the child undergoes treatment, and the complexities involved with the healthcare system, parents are the most knowledgeable informal caregivers for a child with cancer. Thus, parental caregivers are experts in their everyday experiences living with childhood cancer and can make meaningful contributions to health research, ensuring it is relevant to patient needs.

Patient Oriented Research (POR) is one way to bring together patients, family members, researchers, educators, healthcare providers, and decision-makers to actively collaborate to transform and bring about positive change in pediatric oncology (Mallidou et al., 2018). To gain a better understanding of how nurses involved in all aspects of pediatric oncology education, research, and practice can effectively collaborate with families of children with cancer, the tenets, related benefits and challenges, and key recommendations for implementation of POR are presented below.

PATIENT ORIENTED RESEARCH

POR engages patients, their caregivers, and families as partners in the research process (Canadian Institute of Health Research [CIHR], 2019). It involves a shift from the traditional more paternalistic role of the patient or parental caregiver as a passive

receptor, to an equal role as a partner in the research process. Specifically, the CIHR (2011) states that POR “connotes a higher level of engagement of the patient in the clinical research and knowledge translation process”, and “encompasses both clinical research and health services research, the synthesis, dissemination and integration of this new knowledge into the healthcare system and into clinical practice” (p. 1). Involvement of parental caregivers of pediatric oncology patients may include establishing research priorities; developing research questions; deciding on relevant research methodologies; and participating in data collection, analysis and dissemination of findings (Mallidou et al., 2018). By including parental caregivers of children in the research processes surrounding cancer, the research can be made more relevant to children’s and family needs by focusing on meaningful priorities. While some argue that patients and families do not necessarily need to be involved in all aspects of the research process, their involvement affords researchers more specific and relevant research, contextual interpretation, and knowledge translation (Ramsden et al., 2017).

BENEFITS AND CHALLENGES

POR is ultimately aimed at achieving benefits that matter to patients and families, as well as researchers. Researchers who have engaged patients and parental caregivers in the research process have reported that the benefits include the development of relevant research questions, methodologies and protocols, and projects that culminate in research outcomes that are most meaningful to those in similar circumstances

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(Amirav et al., 2017; Baumgardner, 2019; Ramsden et al., 2017; Shen et al., 2016). As a result, POR-oriented research may be seen by parents who participate as more valuable and worthwhile because it is contextually grounded in family-centred and culturally congruent nursing care (Jagosh et al., 2012). Additionally, some authors have suggested that there are higher recruitment and retention rates, as well as lower attrition rates with POR processes than with traditional approaches (Edwards et al., 2011). POR also strengthens relationships between patients, families, communities, and academia; increases the capacity for data collection, analysis, and interpretation; and enhances research sustainability and extension (Macaulay et al., 2012). Similarly, when parents are involved as equal partners in research, knowledge translation may be more meaningful and successful, supporting more meaningful outreach (Ramsden et al., 2017; Shen et al., 2016). Perhaps most importantly, POR supports parental involvement in all aspects of research as it can result in parents feeling empowered, respected, a sense of control, confidence, and being valued as experts in their own experiences with oncology care (Amirav et al., 2017; Domecq et al., 2014; Shen et al., 2016).

However, POR poses a number of challenges for researchers who are including patients, parents, other researchers, and healthcare team members. Reported challenges include parental frustration and loss of engagement given prolonged research timelines, problematic logistics related to financial and human resources, and a perception of power differences amongst team members (Amirav, et al., 2017; Bishop et al., 2018; Kim et al., 2018; Shen et al., 2016). Patients and parental caregivers volunteer their time to engage as research team members. However, with the unpredictability of research processes such as ethical and operational approval, lengthy recruitment procedures, and slow translation of research to practice, parental frustration and disengagement may occur, as time unfolds (Kim et al., 2018).

Another challenge experienced with POR is the financial and emotional

burden experienced by parental caregivers. Considering parental caregivers of children with cancer take on enormous responsibilities for their child's care, involving them in POR may add pressure to their already stressful experiences (Fayed et al., 2018). For example, along with the usual day-to-day care of their child, there are many other logistics and potential burdens of engaging in research. These may include costs for child care, meals, parking fees; an inconvenient timing of meetings; and the emotional toll of sharing their own experience and contemplating the research topic time and again (Amirav, et al., 2017; Edwards et al., 2011; Kim et al., 2018).

Parents may also perceive power inequity amongst the research team members or between themselves and the other members of the team. They may feel nervous, inadequate, or ill prepared to collaborate in large teams or teams that include healthcare professionals who cared for their child. Other challenges for those undertaking POR include finding representative parents and targeting patients and families that are from hard-to-reach socioeconomic areas; locating and recruiting parent partners when the overall population size may be small; and, parental feelings of tokenism if parents are not engaged in the research process in a genuine and meaningful manner (Kim et al., 2018; Shen et al., 2016).

KEY RECOMMENDATIONS

While POR has become more commonplace and is often seen as an important ethical mandate for academic health researchers (Domecq et al., 2014; Shen et al., 2016), there are a number of related challenges as mentioned above. To reduce or mitigate such challenges, it is crucial to co-design research with parents of children in treatment for cancer. To begin, researchers can collaborate with nurses in pediatric oncology to identify parental caregivers who may be interested in engaging in research as a team member, and who are seen as key informants given their experiences in pediatric oncology and the research topic area.

Once the research team is formulated, important recommendations for effectively engaging parental caregivers include early and consistent involvement, and creating time early on for developing mutually respectful and trusting relationships (Domecq et al., 2014; Kim et al., 2018; Shen et al., 2016). Authors have also emphasized the importance of establishing co-produced and clear expectations, roles, duties, and timelines for all research team members to avoid confusion, frustration, and unfair time commitments for parents (Amirav et al., 2017; Ramsden et al., 2017). Similarly, equitable involvement in research can be achieved by designating parent team members as "co-investigators", "parent advisors", and "collaborators" with clearly co-defined roles and expectations (Ramsden et al., 2017). To minimize or mitigate the potential for tokenism, parents require appropriate training and education, which will increase the probability of parental commitment, confidence, and successful, consistent engagement throughout the research process (Kim et al., 2014; Shen et al., 2016). Establishing a positive and supportive research environment is also key to engaging parents in POR including using language that is neither technically laden or offensive; co-planning meeting times and accessible locations; considering the option and feasibility of virtual meetings; and providing childcare, meals, transportation, parking fees, and honoraria (Domecq et al., 2014; Kim et al., 2018; Shen et al., 2016).

CONCLUSION

The many advantages of implementing POR in pediatric oncology are clear and may lead to improvements in all aspects of research from design to knowledge translation. Developing POR likely necessitates changes in the way in which research is contemplated. To mitigate the related challenges of POR, time is well spent early in the research process to identify potential parental partners, develop effective trusting collaborative relationships, and co-design feasible and meaningful research processes aimed at enhancing comprehensive pediatric oncology care.

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