International Journal of Nursing Studies 83 (2018) 91–102

Contents lists available at ScienceDirect

International Journal of Nursing Studies

journal homepage: www.elsevier.com/locate/ijns

Insights from parents of a child with leukaemia and healthcare professionals about sharing illness and treatment information: A qualitative research study

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ARTICLE INFO

Keywords:
Cancer
Children and parents
Communication patterns
Communication intervention

ABSTRACT

Background: Many parents report a strong desire to take on information-giving roles, and believe they are best positioned to discuss their child's illness with their child. Healthcare professionals have a supporting role to reduce the burden on parents who feel responsible for conveying information to their child and other family members.

Objective: To examine parents' and healthcare professionals' perceptions of roles in receiving and communicating information when a child is diagnosed with and treated for acute lymphoblastic leukaemia.

Design, setting and participants: We used the principles of a grounded theory approach. This was a single site study, recruiting from a principal children's cancer treatment centre in the United Kingdom. The sample included parents of children receiving and completed treatment for acute lymphoblastic leukaemia (n = 28), and healthcare professionals (n = 34).

Methods: Methods included individual interviews, face-to-face and telephone, focus groups, and an online forum.

Findings: Communication 'touch points' are many over the course of a child's cancer journey. We describe often 'mismatched' communication encounters where those seeking information and those providing information have different goals. Healthcare professionals in the encounter have expertise at the outset while parents have less expertise, but this expertise grows over time and this can increase the perceptions of this 'mismatch' and create different challenges.

Conclusions: Considered in the context of middle range transition theory, we might suggest that parental foreground (seeking information directly) and background (passive actors) roles are the result of differing levels of uncertainty, and depend on the situation and preferences and child and family needs that may present differently over time in different contexts. Our work contributes to the emerging consensus that communication is more than a core set of skills that healthcare professionals just need to learn: clear specifications of mutual roles, responsibilities and a shared understanding of goals is also essential.

What is already known about the topic?

- Children (primarily between the ages of 4 and 10) have shown a reliance on parents for information, therefore giving parents many important communication roles.
- Many parents report a strong desire to take on information-giving roles within their families, and believe they are best positioned to discuss their child's illness with their child.
- Information provision is not a benign intervention by healthcare professionals, it requires a responsive approach to child and parent needs and preferences.

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https://doi.org/10.1016/j.ijnurstu.2018.04.008
Received 3 January 2018; Received in revised form 29 March 2018; Accepted 12 April 2018

What this paper adds

- Parents sometimes felt inadequately prepared for the level of responsibility they were charged with and in the majority they were not offered assistance on how they could communicate the diagnosis to their child.
- Information was medically-focussed by healthcare professionals, particularly in the 'diagnosis talk', and this established a pattern for all future conversations.
- Assumptions are made about which roles provide particular kinds of information, for example, doctors primarily focussed on the disease and treatment and nurses focussed on care and side effects, both with parents, while health play specialists talked with children.
- Most parents in our study actively sought information that helped them to manage their own uncertainty.

1. Introduction

Recent improvements in survival from childhood cancer (Steliarova-Foucher et al., 2004, 2017), mean that the context of communicating about childhood cancer has transformed over the last few decades. High quality, accurate and timely communication should be prioritised for all children with cancer (Knops et al., 2012). Communication and the transfer of information is known to be complex (Ringnér et al., 2013). Healthcare professionals need to convey information about the child's disease, treatment and prognosis, as well as information that enables parents to care for their child while in hospital and at home, to create an environment of normality (Bjork et al., 2005). Nurses are well situated to share information and be a conduit for the translation of complex information (Citak et al., 2013; Hendricks-Ferguson et al., 2015). Parents must then choose when and how much of this information to share with their child (Mack et al., 2011). More complex, is prognostic disclosure with children, where 'never tell', 'always tell' and 'maybe tell' has been described as a historical continuum, where the individual needs of children and parents have more recently become the priority (Sisk et al., 2016). There is evidence to suggest that children should be involved in decisions that affect them when they are able to do so and that children would like to be active participants in their health care, or at least have the choice to participate (Coyne et al., 2014; Hinds et al., 2001; Zwaanswijk et al., 2007). In one of our earlier studies we talked with children and young people, aged 4–19 years, and described their communication preferences (Gibson et al., 2010). Children (primarily between the ages of 4 and 10) were shown to have a reliance on parents for information, therefore giving parents many important communication roles. The conceptual model we developed described how children (aged 4–12) reside in the background of information sharing with health professionals until they gain autonomy as young people (around age 13). They then move into the foreground, and their parents transition into a supportive background role. Reviewing this model may help younger children realise their abilities to voice their preferences and older children to move into the foreground. Parents and health professionals, in turn, can learn to develop in their supportive background roles. Current perceptions surrounding communication patterns have thus positioned the parent and child in either background or foreground roles. "Being in" the foreground or background depends on children's and young people's dominant perspectives of their own communication skills surrounding their illness, as well as those of others; the notion of a foreground position draws on the Shifting Perspectives Model of Chronic Illness (Paterson, 2001) and its later application to adolescents with cancer (Hinds, 2004) that describe the illness experience as a continually shifting process, as opposed to a linear or phased experience, where patients' perspectives can result in illness or wellness featuring in the 'foreground' based on events such as threat, transition, suffering, or hope, ability to find meaning in life and interactions with others (Meleis, 2010).

The study reported here describes a novel, and ongoing, communication programme. Here, we report on a study that sought to understand more about the roles parents play in the foreground and background, and how healthcare professionals prepare parents for these roles. Together, our studies have informed the development of an online intervention named HELP (Harmonising Education about Leukaemia for Parents) (Bryan et al., 2016).

2. Literature review

2.1. Parents and children need information: why and how much

Though cure is not guaranteed, chances of survival have improved dramatically and questions about how to communicate effectively have focused on supporting children with a life-long chronic illness (Dixon-Woods et al., 2005). It is reported, "for virtually all parents, becoming a parent of a child with cancer marks a striking, biographical shift" (Young et al., 2002, p. 1837). A major part of this shift involves parents taking on information-sharing roles during their child's treatment, most predominantly executive-like roles, managing what and how their children are told about their cancer diagnosis (Young et al., 2003). Three factors described as contributing to restricted parents' communication with their child include: information overload and emotional turmoil, lack of knowledge and skills for disclosing the diagnosis, and assumptions about burdening the child when discussing cancer (Badarau et al., 2015). There is a clear dissonance between parents' desires to be informed in order to make decisions about care and treatment, and the steep learning curve and new language they face at diagnosis (Markward et al., 2013; McGrath, 2002).

The desire to gain control has also been described by children, where they reported knowledge and understanding about their illness and treatment that allowed them to participate in their own care (Darcy et al., 2014). The sharing of information helps children better understand, prepare for, and cope with their illness, the procedures they may undergo, discharge from hospital, return to school, and in some cases, relapse or end-of-life care (Ranmal et al., 2008). Children who do not receive this kind of information early on are more prone than others to anxiety and depression during cancer treatment, and to long-term psychosocial adjustment problems following treatment (Skeen and Webster, 2004). Young children in particular are known to rely on their parents for all of their medical and non-medical information (Aldiss et al., 2009; Gibson et al., 2010). Parents therefore have the onerous responsibility of understanding the information, assessing the appropriate amount of information that should be available to their child, and then disclosing it.

2.2. Parents and children's preferences for information

Many parents report a strong desire to take on information-giving roles within their families, and believe they are best positioned to discuss their child's illness with their child (Clark and Fletcher, 2003). Over 80% of parents in one study wanted to be viewed by hospital staff as their child's treatment coordinator (Mitchell et al., 2006). Parents recognise their own knowledge deficits at the outset, but often desire information even when the information is upsetting (Mack et al., 2006). Some parents choose to actively seek information as it helps reduce their uncertainty, and increases their sense of control (Kilicarslan-Toruner and Akgun-Citak, 2013). Knowledge early on has been shown to help parents gain confidence, feel secure and more able to become a 'member of the team', by being clear about their role and expectations (Kastel et al., 2011). Parents have reported greater satisfaction when information about the diagnosis is frank, and open, and where their privacy was respected, allowing sufficient time to express emotions and have their questions answered (Beltrao et al., 2007): but less satisfaction with the amount and quality of information in the later phases of their child's illness (Ringnér et al., 2011b). In instances where information was not provided adequately, parents sought other avenues