European Journal of Oncology Nursing 24 (2016) 70–78

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

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

Specialist nurse key worker in children's cancer care: Professionals' perspectives on the core characteristics of the role

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ARTICLE INFO

Article history:
Received 23 March 2016
Received in revised form
29 July 2016
Accepted 24 August 2016

Keywords:
Key worker
Nurse specialist
Care provision
Children
Qualitative data

ABSTRACT

Purpose: To describe the development and implementation of the specialist nurse key worker role across 18 children's cancer centres in the United Kingdom, and draw out significant factors for success to inform future development of the role across a range of specialities.

Method: Data were obtained through 42 semi-structured interviews and a focus group with 12 key workers. Framework analysis revealed two main themes: models of care and key workers' perspectives of the role.

Results: Four models of care were identified and described, roles were organised along a continuum of in reach and outreach with either the presence or absence of home visits and direct delivery of clinical care. Key workers' perspectives of the advantages of the role included: coordination of care (being the main point of contact for families/professionals), experience and expertise (communication/information) and the relationship with families. The main challenges identified were: time, caseload size, geographical area covered, staffing numbers and resources available in the hospital and community.

Conclusion: The label 'key worker' was disliked by many participants, as the loss of 'specialist nurse' in the title failed to reflect professional group. Leaving aside terminology, key workers shared core role elements within a continuum of in reach and outreach work and their involvement in direct clinical care varied throughout the pathway. Irrespective of the model they worked in, the key worker provided clinical, emotional, educational, and practical support to families, through the coordination of care, experience and expertise and relationship with families and professionals.

1. Introduction

A cancer diagnosis has a noticeable impact on children, young people and their families. Besides the complexities of treatment, they have to deal with diverse health, social, emotional, psychological, educational and employment needs. As a result they require a range of specialist and general services to meet these needs over a long period of time. However, they might have difficulty finding their way through the system and obtaining the support they need (Cook et al., 2013). These experiences place children and young people and their families at risk for increased psychosocial morbidity and fragmented care (Bultz and Carlson, 2005). One solution is to maximise care coordination, to improve processes designed to streamline and navigate the health-care system (Young et al., 2011).

The National Institute for Health and Clinical Excellence's Improving Outcomes for Children and Young People with Cancer guidance (NICE, 2005) recommended that cancer services should have processes in place to ensure effective coordination between professionals involved in the care of children and young people. Care should be integrated and coordinated throughout the patient's cancer journey. The key worker has been identified to meet this need and was defined by NICE (2005) as, 'A person who, with the patient's consent and agreement, takes a role in co-ordinating the patient's care and promoting continuity, ensuring the patient

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http://dx.doi.org/10.1016/j.ejon.2016.08.009
1462-3889/

knows who to access for information and advice' (p200). Although coordination of care and the key worker role have been recommended since 2005, there is limited research in children's cancer care that relates to implementation and evaluation.

Research from other specialties, and from other countries, can illustrate role development and its potential impact. For example, in adult palliative care the relevance of having a professional coordinating care has been highlighted, facilitating communication between the different professionals involved, someone taking responsibility and with knowledge and expertise to take the lead in supporting the medical and emotional needs of the patient and family (Dunne et al., 2005; Field, 1998; Field and McCaughey, 1998; Gysels et al., 2004; Ling et al., 2013; McIlfatrick and Curran, 2000). In adult cancer care the impact of coordination of care on both continuity and quality of care has also been demonstrated (Cancer Care Nova Scotia, 2004; Cook et al., 2013; Fillion et al., 2006; Freeman, 2006; Freijser et al., 2015; Ling et al., 2013). Cook et al. (2013) identified patient navigation as an important source of support for patients and families dealing with the challenges (emotional, informational, practical) associated with cancer. More specifically, research shows that patients are more likely to understand their treatment plan, access services they need, cope with their illness and are better prepared for consultations and treatments (Cancer Care Nova Scotia, 2004; Fillion et al., 2006, 2009; Freeman, 2006). Continuity of care, the outcome of care coordination, is described as important for both patients and carers (Sharma et al., 2009). It has been associated with improved patient satisfaction, reduced emergency room visits and influenced good patient-doctor relationships (Burge et al., 2003; Smith et al., 1999).

Despite roles being operationalized using different titles, for example, key worker (United Kingdom {UK}, Ling et al., 2013), professional cancer navigator (Canada, United States {US}, Cancer Care Nova Scotia, 2004), and cancer care coordinators (Australia, Freijser et al., 2015), the roles share three core characteristics: provision of information; provision of emotional and supportive care and coordination of services. Evidence shows that patient outcomes are better when nurses lead care coordination (Forbes, 2014). Lack of clarity of the role has however been reported, particularly around terminology used (Prokop, 2016) – in services where there was confusion among key workers about the role, parents were equally confused (Greco et al., 2005); key workers saw no differences between the key worker role and their everyday work (Mukherjee et al., 1999); the title was just a renaming of their role and thus unnecessary (Ling et al., 2013). Despite the lack of agreement towards the title used and constraints to role development, staff views are consistent in the recognition that key working improved multi-agency working and the relationships with families and other professionals (Abbott et al., 2005; Cook et al., 2013; Dunne et al., 2005; Field, 1998; Field and McCaughey, 1998; Gysels et al., 2004; Greco et al., 2005; Ling et al., 2013; McIlfatrick and Curran, 2000; Mukherjee et al., 1999).

2. Purpose

Returning to children's cancer care in the UK, in response to the NICE guidance (NICE, 2005), the Department of Health and National Health Service established an implementation group. In 2007, this implementation group agreed with a suggestion from a UK children's charity CLIC Sargent (http://www.clicsargent.org.uk/content/about-us), to support the full implementation of the guidance a review into the community based care and support needed by children and young people with cancer and their families was required. This resulted in the CLIC Sargent 'More Than My Illness' Project, where 19 key workers' roles for children and young people with cancer aged 0–18 years were established at 18 Principal Treatment Centres (PTC) across the UK: roles were supported and education provided by CLIC Sargent (CLIC Sargent, 2009, 2010). The aim for this study was to describe how these key worker roles had been developed and implemented and to draw out significant factors for success to inform future development of the role, with different patient populations. This research is the first systematic approach to examine how the key worker concept has been developed in children's cancer care.

3. Method

3.1. Design

Using a descriptive qualitative approach, this study focuses on describing the nurse specialist key worker role, defining the core characteristics and ways of working. This was part of a larger mixed-methods study to evaluate the role of the key worker from the perspective of multiple stakeholders to best illuminate the impact of the nurse specialist key worker role on families' experiences (Clic Sargent 2015, http://www.clicsargent.org.uk/sites/files/clicsargent/CLIC%20Sargent's%20Key%20Worker%20report.pdf). This initial exploratory step was well suited to obtaining rich descriptions from those fulfilling the role of a key worker in an effort to understand how the role was implemented and developed locally.

3.2. Setting and participants

Service delivery in the UK for children with cancer is based in specialized principal treatment centres (PTC). The PTC retains overall responsibility for the cancer treatment plan but defined aspects of care are delivered in a Paediatric Oncology Shared Care model provided through designated Units (Paediatric Oncology Shared Care Units {POSCUs}). Shared care refers to care delivered nearer to the families home, where sharing parts of care with a child's local paediatric/ or a young person's designated Teenager and Young Adult local service has been established: however the shared care model is not applied uniformly throughout the UK. There are 19 PTCs and 18 of these across England, Wales and Scotland took part in the evaluation (see Fig. 1).

In each PTC there was a funded nurse specialist key worker (in four PTCs more than one key worker was funded or the initial key worker left the role and was replaced by another nurse specialist key worker). The context where they worked varied, for example not all PTCs had POSCUs, in some PTCs the nurse specialist key worker was linked to a specific cancer type, for others the key worker was defined by the region they covered. The majority supported children and young people aged 0–16. The key worker was, in the main, a specialist nurse experienced in Haematology/Oncology (only three out of the 21 key workers interviewed had less than 10 years of experience working in the field). The key workers' professional background was described as: paediatric oncology outreach nurse specialist ($n = 14$); clinical nurse specialist/specialist practitioner ($n = 4$) and other ($n = 3$). Key workers' caseload composition varied in the number of families supported (median caseload varied between 39 and 51 patients) as well as the diagnosis covered (14 worked with a range of diagnoses, 7 worked only with children with a brain/spinal tumour, leukaemia or with families during the radiotherapy phase of treatment).

3.3. Data collection

Key workers were interviewed twice, using face-to-face individual and group as well as telephone interviewing. The same researcher undertook all the interviews and led the focus group