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

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.

Keywords: key worker; nurse specialist; care provision; children; qualitative data
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 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 specialities, 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 2013;
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 2013), 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); 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).

**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 to 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.

METHOD
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 (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.

Setting and participants

Service delivery in the UK for children with cancer is based in specialised 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 Figure 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 POSCUUs, 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 to 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).

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 discussion (AM). Similar to Ling et al, (2013), and Greco et al, (2005) interview questions focused on the following topics: key workers’ professional background; key worker’s role; frequency and type of contact with families and children/young people; assessment and review of families’ needs; issues encountered in practice; liaison with other professionals and services; training and supervision received. The second interview focused on exploring topics that
needed further development following the first interview in addition to focusing on how the role had developed during the time between the interviews. The focus group (held in one of the nurse specialist key workers annual meetings) aimed to bring nurse specialist key workers together to look at their roles and competencies, what worked well, what had been achieved and what was more difficult. The nominal group technique was used to generate group ideas and consensus (Gibson and Soanes, 2000). The interviews and focus group were transcribed verbatim.

Data analysis
The Framework approach was used to analyze the interviews and focus group transcripts: selected as known to be a flexible and rigorous approach to team analysis (Parkinson et al, 2016). This method involved charting and sorting data into a framework to facilitate comparisons and interpretation of the key ideas and themes emerging from the data. There are five key stages which are closely interlinked (Ritchie et al 2014; Spencer et al, 2003): 1) familiarisation of the data; 2) identifying a thematic framework; 3) indexing - applying the thematic framework to code all the data; 4) charting - grouping the data according to the part of the thematic framework to which they relate; 5) mapping and interpretation. A preliminary framework was developed by AM which then evolved during analysis of the initial transcripts by SA and AM. Analysis was undertaken by two researchers (SA, AM) and validated by a third (FG). Regular meetings were held during the analysis period to check consistency of analysis and to refine the framework.

Ethics
Ethical approval for the study was granted by an NHS Research Ethics Committee (12/WM/0365) and London South Bank University. Local approval was also granted to approach staff in each of the PTCs. Appointed CLIC Sargent key workers received an invitation letter and written information about the study. They were contacted by the researcher (AM), and consent was sought face to face or via telephone. The approach taken to reporting the study was made clear at the outset, to assure all participants that only anonymised data would be reported, with reference to ‘generic key worker roles’, across the service, links to individual services or
specific roles would not be made.

RESULTS

Data were obtained from 42 semi-structured interviews with specialist nurse key workers. The first interview was in 2013 (n=23), the second interview in 2014 (n=19), and a focus group (n=12). Framework analysis revealed two main themes – model(s) of care and perceptions of the role. The first theme describes how in practice the role was developed including: what the role includes; work with families; work with stakeholders; cancer journey; where key workers were based; and how families and key workers were matched. The second theme describes perceptions of the role and includes: key workers’ perceptions of the role and of what characterizes a good key worker; their views on stakeholders’ perceptions of the role; advantages/impact; disadvantages/challenges and obstacles (note: b indicates the quote is from the second interview, other quotes are from the first interview).

Models of care

What the role includes

The role of the key worker was viewed by the post holders as comprising: care coordination, being the main point of contact for children/young people, families and professionals, being a link between the PTC and shared care (where this was in place), assessing families’ needs, sharing information with families and professionals, education for families, training professionals and being an advocate for families and children/young people. Key workers shared a view about their role, although in practice their overall responsibilities were developed in different ways as will be described throughout these findings.

Work with the families throughout the pathway

The role of the key worker changed throughout the cancer journey. Key workers often met the families at diagnosis. They were matched either on diagnosis or geographical area. In the first meeting, key workers introduced the role (a few key workers had leaflets with this information). Giving information and going through the information received was perceived as
an important aspect of the role particularly at this point of the pathway (as families were overwhelmed with their child’s diagnosis). The diagnosis phase was an intense phase with families’ informational and emotional needs at a high level; hence key workers focused on sharing, interpreting the information about the child/young person’s condition and treatment. In addition to information needs, which were a priority at the initial stage, other needs were identified (for example, practical; financial; work and family related needs) throughout the first set of meetings: over time the coordination aspect of the role became more and more relevant.

“there are so many questions and we reassure that the questions that they are having are normal and appropriate, referring them onto others who’ll support them” (Key Worker 14)

“(…) Lots of professionals get involved, and for families that can be very confusing, and they don’t know quite who is doing what where” (Key Worker 8)

Central to the support provided and the work developed by key workers was the holistic approach to needs assessment. A comprehensive holistic needs assessment was carried out by key workers, mainly in an informal way, through conversations between the child/young person/parent and the key worker. Professionals valued the holistic assessment and regular monitoring of the family and patient’s needs and concerns. Families’ needs were reassessed at the end of treatment, if the child/young person had relapsed or had become palliative; if there were any significant changes the assessment would also be updated. Some key workers used the Holistic Needs Assessment (HNA) tool and others used Trust specific forms. Key workers acknowledged that using the HNA provided a clear focus on what issues need to be addressed, it helped them find out more about the whole family and it was a way of having the information in one place; however, there were disadvantages linked with this form: the size, the practical aspects of data entry and duplication with other forms being used by other professionals.

Key workers contacted their families regularly by phone, text, email, at school, in clinic, during inpatient stays and General Practitioner (GP) surgery. They informed and helped parents navigate the services, coordinated appointments so that the family did not have to come to hospital several times for appointments that could be arranged on the same day.

“It’s more than coordinating scans. I mean, yes, but spending time with them when they’re in the clinic, talking to them in the clinic” (Key Worker 18)
Nurses on the ward or in the community were predominantly involved in the direct delivery of care. Some key workers were also involved in the delivery of clinical care; others mainly focused on the coordination of care. Nevertheless, key workers continued to support families: “sometimes they struggle with the children’s behaviour on [a steroid], so they will often ring for advice on what to do, or if there is anything we can do differently” (Key Worker 13).

Most key workers described themselves as paediatric oncology outreach nurse specialists, thus their role as a key worker focused mainly on outreach support, they visited the family at home to deliver care and assess needs. Some helped the families by bringing medication from the hospital pharmacy when they were visiting them at home. They also undertook school visits, with the child/young person or alone, and there were occasions when care was delivered in the school in order to facilitate school attendance and reduce the disruption caused by treatment. This support helped families stay closer to home. The number of home visits was agreed between the key worker and the family. Most families received a first home visit, but the frequency after that varied and was managed in agreement with families’ preferences and treatment needs.

Conversely, there were some key workers who developed their role mainly from the hospital, with an in reach focus. These key workers were mainly involved in the coordination of care, organising treatment, appointments and care closer to home through local hospitals and community teams.

“I do a lot of phoning up and changing scan appointments and things like that for people who obviously just phone me” (Key Worker 20)

In some cases, depending on diagnosis and treatment, children/young people would mainly receive their care closer to home by a local team. The nurse specialist key workers were still the main point of contact in the PTC, they were informed and maintained regular contact with the local teams and were still contacted by families if they had queries or needed support, but would have a role more in the background. Within the group of key workers with a more in reach focus, there were some who were involved in the first home visit or school visit.

Key workers involvement varied across the patients’ journey influenced by diagnosis, the type of treatment, and resources available. Key workers involvement shifted accordingly as
described here: “We’re also involved in the ongoing community visits, because in the region that we cover there’s very little children’s community nursing. So we will do direct clinical care. So we’ll be involved as the child is at home and they’re getting used to the diagnosis and family life” (Key Worker 6).

The palliative care phase is a critical phase where the involvement of the key worker intensified and, some key workers took the lead: “Certainly for the patients needing palliative care we’re very much in the driving seat in terms of assessment of patients’ needs both from a medical, psychological and emotional perspective, looking at drug interventions and the whole co-ordination of their care” (Key Worker 9b). Key workers taking the lead in this phase were key workers with training and experience in palliative care, who managed both the clinical and non-clinical aspects of care. In this phase, even key workers who were not usually involved in home visits, did home visits; the frequency of contacts was higher and there was 24 hour support set up. Key workers informed the parents of the support available, the options of end of life care at home, in the hospital or in a hospice. There were, however, key workers who were not involved, in these cases they would hand care over to other specialist teams: “so we would hand over to them [palliative care nurse team], but you wouldn’t suddenly disappear. You are still part of it, but obviously the care management side is handed over to them” (Key Worker 13)

Work with stakeholders

Key workers worked as part of a larger multidisciplinary team supporting the whole family throughout their pathway. They collaborated with professionals within and outside the hospital including: consultants; community nurses; shared care hospitals’ nurses and consultants; GP; ward and clinic staff; physiotherapist; schools/home tutoring service; hospices; dieticians; pharmacy; ward clerks; acute trust; private care; social workers; local paediatric oncology outreach nurses; advanced nurse practitioner; occupational therapist; psychologists; surgeons; computed tomography staff; speech therapists; clinical nurse specialist; neuropsychologist; play specialist; radiologist. This long list shows how patient’s care involves a variety of professionals, and must by this nature be overwhelming for families. However it is this multidisciplinary approach to care that enables a holistic approach to encompass all
families’ needs. In this context, the key worker played a central role in: coordination of care, organisation of meetings and information sharing between professionals. In practice, regular contact with the teams within and outside the hospital were facilitated by videoconferences, teleconferences and face-to-face multidisciplinary team meetings; these contributed to the communication, information sharing, and relationship between professionals and as a result care coordination. Moreover, key workers shared the view that it was important to involve local teams from the beginning, so that they knew about the treatment and what was going on with the families when they were at the PTC and what their needs would be when they moved closer to home. On-going regular contact with the ward nurses was viewed as an opportunity to inform and support them.

Local resources varied in terms of the competency and knowledge set available. Key workers’ knowledge and expertise was shared with other professionals in training sessions and more informally in their meetings. As described by this key worker: “we’ve skillep up community nurses to give chemotherapy at home intravenously for our leukaemia patients so we’re supporting skills development of local services, again to reduce the number of hospital attendances by the community nurses being able to give some specific chemotherapy drugs at home” (Key Worker 9b).

Models of Key Working

Roles were organised along a continuum of in reach and outreach work with the presence/absence of home visits and presence/absence of direct delivery of clinical care as represented in models 1, 2 and 3. The fourth model includes the palliative care phase (see Figure 2).

In model 1, the key worker role is mainly characterized by outreach support. The key worker is involved in the coordination of care, supporting the family in the transition from hospital to home, visiting families at home and being involved in the delivery of clinical care at home. In contrast, model 3 reflects the work of key workers mainly involved in the coordination of care and not directly involved in the delivery of direct clinical care or conducting home visits. This model included also key workers involved in the direct delivery of care in the hospital. The
coordination aspect of the role is also central in model 2, although key workers in this model do home visits these do not include direct clinical care and have other purposes – such as a first and last visit to speak with the family about their needs; to introduce the community nurse who will support the family while they are at home; if the family is struggling with a particular issue. The palliative and end of life care phase is represented as a separate model (model 4) due to the changes in the role that occur during this phase. In this phase, key workers were more involved in the patient’s care, through home visits and regular phone contacts in conjunction with the coordination of the care and management of the medication (not all key workers were involved in this phase).

The balance between care coordination and direct clinical care was further discussed by key workers in the focus group; these specialist nurses shared an understanding that, although other health professionals might be involved in the delivery of treatments (for example, nurses on the ward or in the community), key workers continue to be involved and to have an important role in the provision of information, practical and emotional support and specialist advice.

“so it’s not just about coordinating or hands on clinical care. It's about educating” (Key Worker, Focus Group)

“I think that’s really important, that we don’t just provide clinical care as being, going and putting up some chemo, good clinical care (...) it’s subtle, using all of your expertise, all of your knowledge and skills in every single interaction that you have with the family” (Key Worker, Focus Group)

In both the individual interviews and focus group there was consensus that the model of care adopted was influenced by the resources available in the community and in the PTC. Some key workers mentioned how sometimes it was challenging to accomplish all the elements of their role, such as home visits, with the resources available and constant demands on time. For others the diversity of what was available in the community meant they had to adapt to the lack of resources in some of the areas covered.

Perception of the Role

Advantages
The perceived advantages of the key worker role are linked with the three core characteristics of the role: coordination of care, experience and expertise and relationship. Specialist nurse key workers were the main link in the PTC for families and professionals; thus there was a clear pathway for both families and professionals and a streamlined communication process between families and professionals and between professionals. Several examples were given of how their expertise and knowledge of local teams, the resources available and the family helped them influence care planning and coordinate care.

“a first point of contact, and, actually, because we’ve all got nursing backgrounds, then we understand a) the treatment process, and we understand the organisation (...) being able to talk to somebody who understood the complexities of a hospital, basically, and, actually, there are so many members of the team” (Key Worker 3)

Key workers facilitated care closer to home through delivery or coordination of clinical care at home, care planning and education of parents and health professionals' training. Some key workers had training in palliative care, advanced communication skills and psychology, thus contributing to an improvement in the support given to children/young people and other family members. Key workers were formally involved in staff training and in an informal way they shared their expertise (for example, on treatment protocols; holistic approach to families’ needs) in the multidisciplinary team meetings and with families in the hospital, at home and over the telephone.

Key workers stated that having someone who monitors, gives expert advice and support allowed families to stay home safely. Additionally, their role contributed to families’ empowerment and trust in the service. Care closer to home also facilitated children/young people’s access to education. This was further facilitated by the key workers through their involvement either directly in school visits and meetings with teachers, school peers, or the coordination of the link between health professionals and the school. This ensured that: staff in the school felt confident and knew how to support the child/young person; support was set up before they went to school (again) and the child/young person was happy with the transition. Overall, coordination of care and care closer to home was perceived as saving the organisation and families’ resources (e.g. minimising admissions).
“at least three or four patients a week I would stop from coming into the day unit or the ward. So I find it quite beneficial” (Key Worker 21b)

Key workers support and impact on families’ experiences was also built on the relationship developed with families. A relationship of open and honest communication and trust built gradually enabled support to be tailored to families’ needs. It was also through the relationship established that the transition back home was facilitated and key workers reflected upon comments regarding parent’s feelings of security and enhanced confidence. The relationship with the family was enabled by seeing the family at home. Being able to talk in the home environment facilitated the discussion of the families’ needs and also the relationship between the family and the key worker.

“(…) whilst in a home environment if there is something they want to bring up then they’re more free to discuss it, and I think they’re more inclined to talk openly at home than what they do sometimes in hospital, because of the time pressures, they don’t want to be wasting your time, whereas at home actually you are the focus for that individual” (Key Worker 3)

Challenges

The main challenges in fulfilling the key worker role were: time, caseload size, size of geographical area covered, staffing numbers and inequality of local services. As a consequence, clinical aspects of the role had to be prioritised, leaving less time to provide emotional support for families; it also made the service potentially not equitable, with a focus on newly diagnosed patients and/or those with complex needs. Likewise, increase in caseload and/or large caseload led to pressures on the key worker and service delivery.

“I suppose time is a huge issue, just timeliness, as well, because the information is only relevant for the time that it is there” (Key Worker 5)

In some areas key workers reported lack of support as challenging in the coordination of care. For example, if key workers were not informed of new patients, they would not be able to be present at the initial diagnosis conversation or if the key worker was not informed about a patient going home they were not able to support discharge planning. Therefore, there was an initial effort from key workers to inform other professionals about the role and what they could
Managing expectations was essential as the key worker should not be expected to do everything; they are part of the multidisciplinary team and their expertise and experience should be used to support the family and not to do what other professionals could/should do. It should be a team approach.

Coordination of care was a central element of the key worker role; there were, however, concerns about the danger of the role becoming too administrative-focused, with little time for seeing patients face-to-face. Time was also needed to get to know what was available locally, to know local teams and resources available, and to establish links and relationships; contributing to seamless care. Time management meant also that key workers had to manage families’ expectations on what the key worker could and could not do. The key worker was the main point of contact for the family, yet they acknowledged that they could not be the only point of contact. Key workers expressed concerns about how their role was covered when they were on leave. In some Trusts a team approach to the key worker service was used to overcome this challenge.

*Key worker characteristics and label*

The attributes of a good key worker identified by the participants included on the one side, attributes needed for the coordination of care (such as organised; good time management; willing to seek advice from others; able to signpost; understanding of treatment process; experienced; knows the organisation; understanding community working) and on the other side the attributes needed for the relationship/partnership with families (for example, being friendly; a good communicator; being approachable; nice; empathetic; supportive; compassionate; ‘able to say no’; has a sense of humour; and can advocate for the family).

While all participants praised the role, the attitude towards the label was less positive. For most, the introduction of the key worker label did not reflect a new role as many elements that were specified within the remit of the key worker role – both clinical work and emotional support – were considered to already be integral elements of the existing clinical nurse specialist remit. The new title was also viewed as being potentially confusing for children, young people and their parents. Professionals believed that the label ‘specialist nurse’ was
more informative; hence, some did not use the label in their interaction with families and believed families would know them by their name or as a specialist nurse. Even though some key workers used the label and have leaflets and letters identifying themselves as key workers, they perceived family members might still think of them as the specialist nurse.

**DISCUSSION**

The key worker role has been implemented in 18 Principal Treatment Centres across England, Wales and Scotland. There are core shared characteristics as well as variety in the development and implementation of the role to meet local need. Consistent with emerging literature and evidenced in this study, the key worker role centred around three core functions. It is through these core functions the study findings will be examined: coordination of care (being the main point of contact for families and professionals in the hospital/community), experience and expertise (e.g., communication and interpretation of information to/for families and professionals) and relationship (approachable, compassionate, open and honest relationship and communication between key workers and family members).

Care coordination was facilitated by key workers’ experience and knowledge of how to navigate the system within their hospitals and experience of working with the community services (for example, they knew how professionals worked in local hospitals and in the community and the resources available) and was mentioned by all key workers, albeit in practice it took different formats. Research has shown that when care is well coordinated patients experience effective flow of information between clinicians throughout the course of their illness, with streamlined service provision in response to their physical, emotional and social needs (King et al, 2008; Young et al, 2011). In addition, research has highlighted the role of expertise and experience in the success of the roles focused on care coordination (McKenna et al, 2004). For example, discharge planning was optimized due to key workers individualised support given to parents through the identification of potential problems and solutions, the support available in the community and integration of community nurses (Flury et al, 2011).

Care coordination and being the main point of contact required a holistic approach to families’ needs; needs assessment was a central aspect of the role. Families’ needs are often
wide ranging and likely to change during treatment; hence key workers had a holistic and systematic approach of assessing and reassessing families’ needs. This has been identified as a component of successful home care (Wong, 1991). Most key workers used an informal approach focused on the individual needs of each family, instead of going through a formal assessment form. Nevertheless, formal assessment forms were used as a guide and reminder of the different areas of families’ needs throughout the cancer journey.

The emphasis of the role upon patient holistic assessment, support, education, information and continuity of care within a multidisciplinary team framework was shared by all key workers. However, in practice some key workers were mainly involved in outreach support, others had more occasional home visits and there was a group of key workers who were not involved in home visits. Key workers who were mainly hospital based set up support in the community and were available for telephone support. Having a professional as a link with the hospital and receiving care at home has been described in previous research as less stressful and more convenient for patients (Vooght and Richardson, 1996). When families are able to have care delivered at home, there are fewer financial and time costs and less disruption to work and family schedules; children/young people have more time to play/study, engage in normal activities and have improved school attendance (Close et al, 1995; Escalante et al, 1997; Holdsworth et al, 1997; Lashlee and Curry, 2007; Stevens et al, 2006); in addition, by shortening the stay in the hospital, children and young people’s quality of life can also be increased significantly (Clarke, Fletcher, & Schneider, 2005); hence facilitating care closer to home was one of the aims for the role (CLIC Sargent, 2009).

Similar to Ling et al (2013) in adult cancer care, one of the most important functions of the role was communication and interpretation of information and information sharing with the families and between families and professionals. McCaughan (2002) found that if nurses reneged on this role the patients often sought information from non-professionals. Expertise and experience are also central in the role of the professional cancer navigators and cancer care coordinators in Canada and Australia. In particular, in Nova Scotia and Quebec, the role of professional cancer navigator is fulfilled by specialized oncology nurses, registered nurses with enhanced knowledge and skills in oncology (Canadian Association of Nurses in Oncology, 2006;
Cook et al, 2013). In Australia, cancer care coordinators are registered nurses with a post graduate degree and with at least five years of experience in cancer nursing (Cancer Nurses Society of Australia, 2008). Research shows that nurses with more advanced training were more likely to perform activities in the categories ‘direct caregiver’ and ‘educator’ (McMillan et al, 1995; McKenna et al, 2004).

Having a main point of contact was perceived as an important aspect of the role. This concept echoes what Young et al (2011) describe as continuity of care, in particular continuity within relationships. Families had someone who knew what was happening and someone who had the knowledge to support them. Families preference for having someone known to them has been reported elsewhere (Cook et al, 2013; Dean 2006; Ling et al, 2013; Fillion et al, 2006, 2009). Continuity of care has also been identified as necessary to promote children’s achievement of an everyday life where the child feels safe, in control and included (Darcy et al, 2014). The relationship established with families and professionals was a central aspect of the role. Open communication between the key workers and families was a continuous essential element of the support given and received, a factor also recognised by Williams and Sidani (2001). This relationship was considered helpful in allowing families to feel confident at transition points, for example when the care at home was mainly delivered by the community teams.

Contextual factors influenced the development of the key worker role. Key worker’s involvement in care coordination and home visits, were influenced by the resources available in the PTC and within the community, these included staff and caseload numbers. Time constraints hindered the implementation of the key worker role as reported elsewhere (Abbott et al, 2005, Greco et al, 2005). Coordination of care and family support are only possible if key workers have time to fulfill all the aspects of their role as reported by Sloper et al (2006).

The post-holders’ perspectives on the characteristics of a good key working echoes the traditional nursing roles of providing holistic needs led and psychosocial care (Leigh, 1998), but it also includes characteristics needed for coordination of care. Consistent with the findings reported with key workers in adult cancer care (Ling et al, 2013), specialist nurses had a negative reaction to the label ‘key worker’, which reflects staff feeling that the label diluted
their professional identity and did not capture their professional competence. Despite these shared concerns of role title, as evidenced here, and may prove to be of more importance to families in terms of outcome, is the key working model of care.

**LIMITATIONS**

The study has limitations that should be considered when interpreting the results. The interviews represent a snapshot in time of post-holders’ views of the key worker role and the role is continuing to develop and change. The opinions expressed by key workers about the degree to which the role had been embraced by stakeholders and family members did not include any input from stakeholders and families: their views were captured later as part of the larger study ([http://www.clicsargent.org.uk/sites/files/clicsargent/CLIC%20Sargent's%20Key%20Worker%20report.pdf](http://www.clicsargent.org.uk/sites/files/clicsargent/CLIC%20Sargent's%20Key%20Worker%20report.pdf)). In addition, this is a reflection on the key worker role within children’s cancer care in the UK, as such the findings can not directly be generalized to other contexts or populations. However, as the findings concur with previous work focusing on different patient populations in different countries we might suggest that such resonance indicates similarities, which would be evident in other key worker roles.

**CONCLUDING THOUGHTS**

The key worker role is instrumental in enabling families and patients to access and navigate services. The complexity of families’ needs is reflected in the complexity of the role. Key workers developed their role 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 within, the key worker provided clinical, emotional, educational, and practical support to children, young people and other family members, through the coordination of care, experience and expertise and by forming a relationship with families and professionals. Similar to others, such as Prokop (2016), we have provided a description of the key worker role that confirms care coordination as more than management of a disease or providing information, and aiding transition between points of care. Contextual constrains did however influence the
way the role was developed and implemented: addressing these issues will ensure equitable, seamless, and safe quality care for all children and young people and contribute to an improvement of families experience.
REFERENCES

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Fig. 1. Map of PTC’s taking part in the evaluation
Fig. 2. Specialist Nurse Key Worker Models of Care