What is the role of the children's community nurse in childhood cancer care?

Abstract

Aim: To highlight the experiences of children's community nurses (CCNs) within cancer care and to identify their day-to-day roles and responsibilities. Method: Questionnaires were completed by 12 CCNs and oncology specialist nurses within London, these were analysed using a coding software. Findings: Children and their families perceive CCNs as knowledgeable, happy and friendly professionals, essential in reducing hospital admissions and who have a positive impact on a child and their family's well-being. The CCN has a varied role in cancer care, however, currently in the UK there is no framework specific to caring for a child at home with cancer. In response to the findings, one has been written to identify care needs and to emphasise service expectations.
Conclusion: Specific training for caring for a child with cancer should be prioritised for all staff working within a CCN team and to ensure best practice, the framework should be implemented once reviewed and services re-evaluated.

Key words

Childhood cancer, cancer care in the community, community nursing, children's community nursing

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In the United Kingdom, cancer affects one in every 500 children under the age of 15 (Office for National Statistics, 2020), the most common types being leukaemia and brain tumours. Children's community nurses (CCNs) are a group of professionals working together alongside principal treatment centres (PTC) and local shared care units to provide care. The CCNs aim is to reduce hospital visits, reduce infections and try where possible to help the child to live as normal a life as possible (The Queen's Nursing Institute, 2018). Episodes of care often included administering intravenous antibiotics and chemotherapy, wound management, phlebotomy and enteral feeding. However, at present there is no framework for CCN teams, particularly in relation to cancer care, therefore CCN services throughout the UK vary.

Background

There are many advantages of receiving care in the community, be that in an educational setting or at home (Green, 2019). Children undergoing cancer treatment and families want to feel a sense of normality by attending school and seeing friends, and parents want to continue working (Hansson et al, 2012; Darcy et al, 2019). Both parents and children may at times feel isolated and lonely, as a result of attending multiple appointments and having long admissions for treatment, or due to complications (Bjork et al, 2009; Gibson et al, 2010; Darcy et al, 2019). Support from CCN teams can have a positive impact on the child and family's quality of life, children were able to be seen at a time suitable for them and their family (Castor et al, 2017). Support from a CCN team can reduce pressures on the family, both emotionally and financially (Green, 2019).

However, there is a paucity of literature identifying what procedures or treatments were carried out by CCNs in the community (Green, 2019). Most of the studies were European and were therefore not generalisable to the UK due to dissimilar health services.

Aim

The purpose of this study was to highlight the experiences of CCNs within cancer care and to identify their day-to-day roles and responsibilities.

Methods

Initially, both quantitative and qualitative research methods were explored, however quantitative methods require a large number of participants for the research to be truly valid and generalisable (Parahoo, 2014 ; Boswell and Cannon, 2016; Borbasi et al, 2019). It was decided that the research would benefit from experiences to allow a deeper interpretation of the data, which would be gained through a qualitative study (Polit and Beck, 2017; Houser, 2018). A purposeful sample group was chosen because as Lathlean (2015), Parahoo (2014) and Luciani et al (2019) explain, it is the most effective way of extracting specific information from participants in nursing research and maximises the efficiency of the data collection. CCNs and specialist shared care oncology nurses were identified as suitable participants. Children and families were excluded from the study

Table 1, Inclusion/exclusion criteria

Inclusion	Exclusion
• All CCN teams within the 12 inner boroughs of London who have children with hematological and oncological conditions. Including palliative and newly diagnosed patients. • Paediatric clinical nurse specialists who have a role within shared care within the 12 inner boroughs. • Participants must work within the NHS. • Nurses of various experience currently working within and CCN team.	• All CCN teams outside of the inner boroughs of London. • Administrative or allied health-care professionals. • Private, non-NHS-funded CCN teams.

due to ethical dilemmas such as consent (Institute of Medicine, 2004).

Inclusion and exclusion criteria were used to determine the participants' ability to answer the research questions (Borbasi et al, 2019; Tappen, 2011). The sample area was defined as the 12 inner boroughs of London. Due to small scale research study and to research within personal limits

Focus groups, interviews and questionnaire methods were originally explored; however, it was decided that focus groups and interviews would have been costly in time to transcribe (Boswell and Cannon, 2016; Houser, 2018). A questionnaire was chosen to capture self-reported observations, which as Jones and Rattray (2015) and Wood and Kerr (2011) agree can be electronically sent to a large volume of participants, few costs are involved and they can easily be analysed using coding software. Coding software was used to streamline data collection and ensure efficiency of the data analysis. Initially, 14 open-ended questions and 1 tick box closed question (the latter was used to gather quantifiable data to strengthen the findings) were created. However, following peer review and discussion, 12 questions were finalised. These reviewers did not participate in the study.

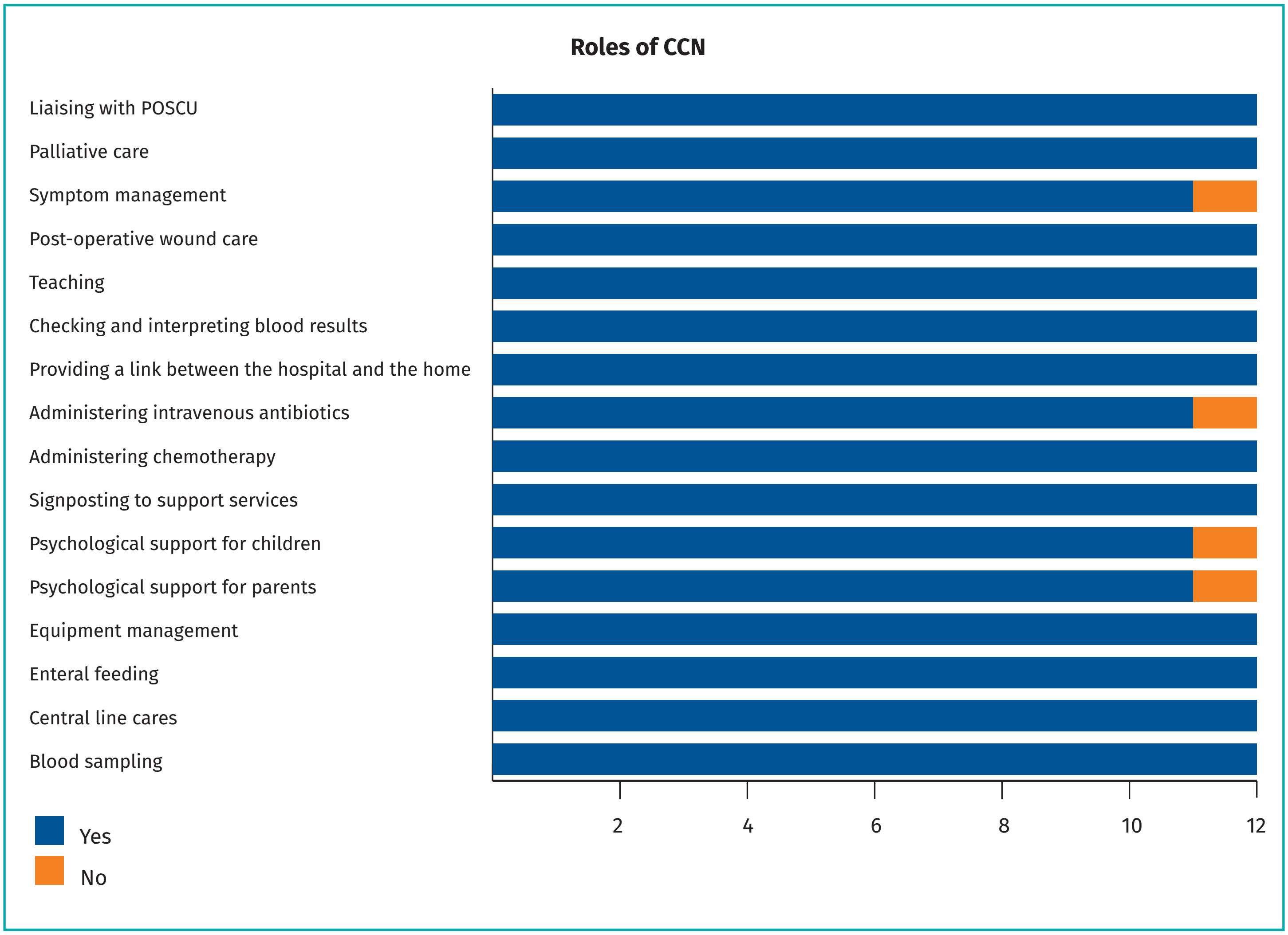

Figure 1. Roles of community children's nurses

No private, non-NHS funded CCN teams were identified in the sample area of central london. Five CCN teams from within the 12 inner London Boroughs were identified as the sample group, emails or phone calls were made to each service lead to discuss consent for participation.

Four of these teams consented for the questionnaires to be sent via email, the fifth did not respond. Three oncology specialist nurses within the area also consented to be part of the study. Questionnaires were sent electronically via secure email to the participating teams. Nine CCNs and three specialist nurses returned the completed questionnaires which were analysed using MAXQDA (2020) software. In Vivo coding and thematic analysis were used to systematically process, identify and analyse the data from the questionnaires (Braun and Clarke, 2006; Manning, 2017; Saldana, 2016).

Ethical considerations

In addition to the questionnaire circulated, an information document was given to all participants to ensure the research intentions were understood and that confidentiality and anonymity were guaranteed. The document instructed that no information making patients or families identifiable should be used and returned questionnaires should not be personally named so that the researcher could not link any response with a participant. Furthermore, all completed questionnaires were stored on a password protected electronic device, stored in a locked cupboard when not in use. Participants were informed at the beginning of the study that they would be able to withdraw at any point without consequence.

Ethical approval was granted by the ethics committee within Buckinghamshire New University and supported by Central London Community Healthcare Trust.

Findings

The main themes identified through the findings include:

- Roles and responsibilities
- Positive feedback
- Maintaining normality through treatment
- CCN experience and education
- Limited chemotherapy treatments available to give safely in the community.

Roles and responsibilities

Table Two exhibits the statistical findings for Q12, which asked each participant to tick the appropriate episode of care carried out by the CCN relating to cancer care. This data was then analysed and found to be consistent with the qualitative responses from Q1-11 and led to the framework being developed.

In answer to one question, 'In your opinion, why are children with cancer visited by a children's community nurse?' participants of varied job roles answered with consistency.

> *'To avoid them having to go into hospital for episodes of care that can be provided at home.' Participant K, CCN Team Lead*

> *'To limit hospital attendances, to obtain blood samples and give certain chemotherapy, carry out line cares, provide symptom management support, support with enteral feeding.' Participant J, CCN Team Lead*

> *'To prevent them needing to attend hospital for routine procedures like blood sampling or dressing changes or medications'. Participant D, CCN*

> *'Minimise time children have to spend in hospital. They can have "normal" routines school etc. while having nursing cares attended to. Less disruptive to family life.' Participant L, Oncology Specialist Nurse*

The questionnaire collected data for which specific skills and cares were carried out by CCNs on a day-to-day basis. The formulation of a standardised framework would ensure these episodes of care are delivered with consistency across NHS trusts.

One hundred percent of participants agreed that part of a CCNs role is liaising with POSCU (Paediatric Oncology Shared Care Units); when asked, 'What do you understand by the term POSCU?' responses were similar, which showed consistency of the knowledge and understanding of the role of POSCU. Eight of the 12 participants agreed POSCU was a form of multidisciplinary working including PTC (Principal Treatment Centre) and local hospitals and six participants mentioned the primary role of ensuring care is available close to home, two specialist nurses highlighted this is usually within 1 hour of the child's home. In response to this question, one CCN (Participant B) wrote:

> *'This is the local team which supports the child when not being cared for by their main tertiary centre, they provide some treatment locally which keeps the child closer to home and helps reduce the pressure on the larger centres of care'.*

Participant H, a specialist oncology nurse wrote:

> *'A hospital that works in conjunction with the PTC and provides supportive care closer to home'.*

Nine of the 12 participants similarly acknowledged that children and their families travel considerably less than if they were required to attend the PTC for their treatment, enhancing their quality of life, which highlights the importance of community care.

Positive feedback

According to Hansson et al (2011) and Darcy et al (2019), children are happiest when they are cared for at home where their families and parents are less stressed or anxious. Therefore, it is important to understand how community services are perceived by asking about the experiences of the nurses working within the homes and in the hospitals, reviewing the consistencies or inconsistencies. When asked, 'How do you think the children and their families perceive the service given by Children's Community Nurses?' All 12 participant answers were positive, the most common word used was 'grateful'. Participant C wrote,

> *'Wonderful service, very helpful, great team'. Others wrote helpful, friendly, knowledgeable, approachable, respectful, happy, fun, flexible, consistent, family-friendly and supportive.'*

Similarly, specialist nurses confirmed from their perspectives, adding to the validity of the results, being from separate teams who are less likely to be biased. Participant L, a specialist nurse wrote:

> *'always get excellent feedback and express how grateful they are for the service'.*

Participant H, specialist nurse, also stated:

> *'They appreciate it, mostly all of the families that use our service say they are grateful for the service we provide, that they didn't have to go to the hospital all the time.'*

These statements are in line with Carter et al (2012) and Castor et al (2018) who found similar supporting themes.

Maintaining normality through treatment

Having understood the CCN service is appreciated by families, it is important to understand why. Being able to maintain children and their family's routine was one theme which emerged throughout the questionnaires and in previous literature (Bjork et al, 2009; Castor et al, 2018; Darcy et al, 2014) highlighting that CCN visits to school, nurseries, after-school clubs or attending before school to complete episodes of care contributed to this. Participant E, a CCN, stated the service 'enhances their quality of life by making it possible for them to do their daily norms'. Participant A wrote:

> *'Many people are grateful we are able to treat their child/themselves (teenagers) at home/school. They value the time they are able to spend with their children within their homes, establishing daily routines and normality'.*

Similarly, Participant B wrote:

> *'Parents and families can have a sense of normality and continue with normal daily living i.e. attend school as CCNs can see them there.'*

These quotes all depict a similar idea that CCN teams are positive in promoting normal daily activities for the child and the family.

To ensure children are cared for safely in the educational setting, a select group of teachers, assistants and first aiders are offered training in how to support the child. This includes the safety of the Central Venous Access Device (CVAD), emergencies and basic understanding of the child's condition. Participant E wrote:

> *'Providing training with the school so he/she is safe.'*

Participant K also agreed by writing:

> *'Provide Hickman line training, training the teacher and other staff members what to do in an emergency.'*

If the child requires extra learning support, an Education and Healthcare Plan (EHCP) will be introduced, with which the CCN will provide information. Participant E conferred 'Complete an EHCP if required'.

Travel time was consistently noted throughout the questionnaires, exploring the positive aspect of community care which reduced hospital travelling time, reducing possible infections acquired from taking public transport and the cost of taxis. Six participants explored this in their answers. Participant E wrote:

> *'Parents have to rely on family friends to pick up the sibling from school or the sibling gets taken out of school as well, CCN services take the pressures away from the parents.'*

Participant G also noted:

> *'Parents fear child will pick up infections on public transport and it is expensive to travel in taxis.'*

CCN experience and education

Most of the findings were positive in gaining a clear direction of the skills, responsibilities and episodes of care carried out by CCNs, especially by using the quantifiable answers from Question 12. However, a theme emerged highlighting a difference in the amount of CCNs who had ticked yes to the administration of chemotherapy in the community being their role, and the five out of eight CCNs who had completed the relevant competencies to enable this. Positively, though, six out of eight CCNs had attended a POSCU study day which would have given them the knowledge and understanding surrounding cancer treatments. As well as this, it was evident that having good knowledge impacts care given to patients and impacts the CCNs ability to recognise problems to do with their treatment such as side effects of chemotherapy.

When asked, 'What are the disadvantages of receiving care in the community?' Participant H wrote:

> *'Often a problem can arise for example a sore throat. It would be helpful to have certain bloods taken or swabs but this cannot be done if the equipment/bottles are not taken. Depends on the level of expertise of the nurses caring for the child in understanding the symptoms and concerns.'*

Similarly Participant J wrote:

> *'some staff are not familiar with cancers/leukaemia and so less knowledgeable of treatment plans/side effects.'*

These comments imply a requirement for all CCNs to undertake sufficient education so that there is consistency in the care given to patients in the community, and to ensure best practice. These statements are supported by similar findings from Hansson et al (2012), Randall (2012) and Whiting et al (2015) who imply the need for further education to ensure all community staff have adequate knowledge of the child's condition.

Limited chemotherapy treatments available to give safely in the community

Cytarabine is the most common chemotherapy given to children in the community, however, this service is not available for all and results in many children attending hospital. This is mainly due to the skill mix of staff and service working hours, three participants including two nurse specialists and a CCN team lead noted additional chemotherapies could be given in the community if safe. When asked, 'Are there any services CCN teams could provide to children with cancer that they do not currently?' Participant K wrote:

> *'not unless there were other chemotherapies that were suitable for being administered at home'.*

Participant F noted this is happening within another team in London. However, this team did not partake in this research:

> *'I am aware that some CCN teams who include ANP (advanced nurse practitioner) are able to fit for chemotherapy who are trialing IV vincristine in the community'.*

The nurse also added:

> *'not all CCN teams are chemo givers/work weekends + bank holidays so the service can be very variable amongst teams.'*

These quotes suggest a variation in services, which could be improved by educating staff and adopting a framework to ensure practice is consistent.

Discussion

The QNI (2018) has highlighted the standards for CCN education and practice, which aligns with the vision set out in this framework to ensure CCNs area adequately equipped to treat, manage and support with the episodes of care highlighted in *Figure 1*. Training needs should be taken into account to ensure best practices are carried out in all CCN services.

Previous research studies and the participants in this study agree that care given at home or as close to home as possible benefits the child and family, helping to maintain some normality throughout their treatment and families appreciate not having to go to hospital (Castoret al, 2017; Carteret al, 2012; Gibsonet al, 2010). Having said this, some participants reported variations between services. To improve consistency, a standardised framework would be of benefit (Moulin et al, 2015) and as a result of the analysis of the research, recommendations have been made to improve practice (*Figure 2*).

Limitations

Although CCNs were the chosen participant group for this study for the purpose of obtaining specific information as suggested in the literature (Luciani et al, 2019), there is a risk of bias. CCNs might not want to openly share negative feedback especially in relation to advantages and disadvantages of care in the community. This was minimised by ensuring anonymity, however, and caution was taken while reviewing the questionnaires. The participant group was restricted to a relatively small area of the UK, but because of the large population size with varying demographics, the research was deemed generalisable to the UK in areas that have access to community nursing teams. In addition, the response rate was poor at 5.76%. Having decided to send the questionnaire via electronic means to the teams' shared email system, this relied on the questionnaires to be disseminated out and to be sent back via email. In hindsight, an electronic questionnaire might have appeared easier and quicker to complete, likely increasing the response rate.

Conclusions

Using questionnaires, this research highlighted participants' views and experiences surrounding CCNs and the services provided. Data analysed using MAXQDA identified consistencies and inconsistencies in the episodes of care carried out by CCNs and highlighted the need for standardisation across CCN teams, which would be assisted by a standards framework. This would ensure all children and young people have access to community care, minimise hospital admissions and ultimately reduce infections, improving quality of life.

Recommendations

- All CCNs should attend a POSCU study day (or equivalent) within 6 months of joining a CCN

Framework

This framework should be used in collaboration with local cancer care measures and defines the role of a CCN in children's cancer care. It should be disseminated to ensure consistency of services within the UK.

The role of the children's community nurse within childhood cancer care is varied, and should be interpreted by each CCN team individually, depending on the service and resources provided. Each team should strive to deliver each nursing duty as outlined within this definition, and this should be used to identify service improvements within each team.

It is the responsibility of everyone who works within a CCN team to contribute to the main, collaborative role which is to ensure all children with cancer are cared for at home or as close to home, when possible. This is due to the high level of evidence found that receiving care at home significantly improves a child and their family's quality of life.

Any treatment, procedure or supportive care which does not require a hospital admission should be carried out at home where possible. Those procedures which carry a high risk to the child should be exempt from this, for example treatment for febrile neutropenia.

The fundamental aim of the CCN service is to reduce admissions to hospital by carrying out care in the community. It is the duty of the CCN to assess where care might be best given and to ensure a holistic approach is used, including communication with parents.

Areas deemed suitable for receiving CCN care: home, school, nursery, medical centre, after-school club, carers' home.

Consent must be given by parents prior to visitation, if parents are not present, the child must be given the option for an advocate or chaperone, such as a school teacher.

All children requiring anti-cancer treatment should have the following treatments, support and nursing cares carried out in those settings as mentioned above to promote normality, reduce the risk of infections and improve their quality of life.

All CVAD cares such as dressing changes, flushing of lines to ensure patency should be carried out in the community. Where problems occur with devices not working as they should, CCNs should troubleshoot using their local protocols. For example; using alteplase or urokinase to unblock a device. Hospital attendance should be avoided as much as possible, except in an emergency, for example an accidental line removal.

All children have the right to an education, therefore appropriate teaching must be given to schools so that they feel confident in maintaining a safe environment for the child to receive education. Prior to each school year, CCNs should communicate with each school to ascertain whether further teaching is required, for instance if the child has moved year groups or classes.

All blood tests should be carried out in a community setting in collaboration with the medical team's request. If the results are not readily available to the requesting professional on a centralised viewing system, the CCN is responsible for sourcing the results directly from the laboratory and sending them to the requesting professional in a timely manner. Once results are received, the CCN should have the knowledge to understand whether urgent action is required and should notify the appropriate medical team.

Where possible, anti-cancer medication should be given at home and appropriate education should be provided for nursing teams so they can facilitate this. Granulocyte colony-stimulating factor (GCSF) injections should be given by parents with the support of the nursing team.

At all times, CCNs must work collaboratively with the child's principal treatment centre, oncology shared care unit and all other professionals involved with the child. Effective communication should be used throughout the working day and recorded securely, in a timely manner in accordance with the local record-keeping policy. Safeguarding procedures should also be followed and advice sought when required.

To ensure the emotional and psychological needs of the child and family are met, support should be offered. If it is not available within the CCN team, referrals to other professionals should be considered, for example psychologists.

Where possible, palliative care and symptom management should be carried out at home, in partnership with medical staff and with clear guidance. A child should be able to pass away in a place chosen by them or their family, the CCN should therefore facilitate their wish where possible, taking into account staff experience and resources.

During the cancer treatment, some children will require surgery and other urgent procedures such as treatment for febrile neutropenia. To ensure admissions to hospital are not prolonged, appropriate discharge planning is required. This includes ensuring equipment is available such as an intravenous infusion pump to enable the administration of antibiotics. General practitioners may need communicating with, to ensure suitable dressings and medications are dispensed.

Children who suffer from mucositis may require support with oral hygiene. This may include organising GP prescriptions for mouth care supplies. Nutritional support may also be required if, for example, artificial feeding is commenced. The CCN should work with the family and dietitian to help with feeding tubes, this includes ensuring the family has adequate equipment and stock.

The role of the CCN in childhood cancer care is ultimately to carry out the many tasks, nursing duties, care or support in the community that enable a child to lead as normal a life as possible.

Figure 2. Framework

team. This is to ensure the consistency of knowledge between all staff members, to increase confidence with spotting oncological emergencies, to reduce parental anxieties and to ultimately provide safe practice. A 3 yearly update is also recommended as treatments and guidelines change regularly.

- Consistency between CCN services should be improved by working towards a standards framework, to ensure all children undergoing treatment for cancer have access to care at home or as close to home as possible. The proposed framework has been peer reviewed by one senior team lead and one specialist service manager for a CCN team in Central London during this research process. Therefore, the framework will require further consultation with community services and agreed in line with shared care facilities prior to its implementation, as well as piloting.
- Once the framework has been agreed and implemented, further study is necessary to evaluate the use of the framework and to assess its effectiveness. This would be carried out in the form of a service evaluation encompassing the experiences of CCNs, specialist nurses and if ethical approval is sought, children and their family's experiences would also be favourable. **CHHE**

KEY POINTS

- CCNs are pivotal members of the multi-disciplinary team surrounding childhood cancer care and the patient's journey to recovery.
- A standardised framework would benefit patient care, if followed, by ultimately reducing admissions to acute care and reducing hospital-acquired infections.
- The quality of life for both the child and family is positively affected when a CCN team is available to them by allowing families to gain some normality in such difficult times.
- Services across London are varied, for example cytarabine is available in some CCN teams but not in others. More training is required for those CNN teams who do not currently offer this service to ensure care is standardised across London.

REFLECTIVE QUESTIONS

- What can health-care organisations learn from this study?
- What further research is required to enhance the validity of this research?
- How can we put this framework into practice?

Conflict of interest: None to be declared

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APPENDIX 1. QUESTIONNAIRE

The questionnaire consisted of the following 11 open-ended questions and one tick box question (question 12, see *Figure 1*)

1. Please state your job role.
2. In your opinion, why are children with cancer visited by a children's community nurse?
3. What are there benefits to the child/family receiving care in the community?
4. What are the disadvantages of receiving care in the community?
5. What do you understand by the term Paediatric Oncology Shared Care Unit (POSCU)?
6. A) What are the advantages of a POSCU?
   B) What are the disadvantages of a POSCU?
7. How do you think the children and their families perceive the service given by Children's Community Nurses? Please summarise any feedback you have received.
8. Have you ever received training or education relating to caring for children with cancer? If so, what?
9. What do you think are the main differences between receiving care in the community to the hospital?
10. On average, how many children with cancer does your team visit face to face per week and how long do these visits last? (If you are hospital based, state approximately how many children you see in clinic or have telephone interactions with).
11. Are there any services CCN teams could provide to children with cancer that they do not currently?

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