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Palliative care professionals' perceptions of barriers and challenges to accessing children's hospice and palliative care services in South East London: A preliminary study

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Declaration of conflict of interest

The authors declare that there is no conflict of interest.

Abstract

Objectives: Several barriers have been identified as preventing or delaying accessing to children's palliative care services. The aim of this study is to further explore such barriers from palliative care professionals' perspective from two London boroughs.

Methods: Qualitative- five children's palliative care professionals perceptions obtained from semi-structured interviews.

Results: Three themes emerged: availability and adequacy of child palliative care (e.g., unreliability of services), obstacles to accessing palliative care (e.g., logistical challenges) and cultural values and family priorities.

Conclusion: These findings contribute to the equal opportunities dialogue in this sector and the need for future research to address the challenges identified.

Keywords: children, hospice, palliative care, paediatric, barriers and challenges

Introduction

Children with life-limiting or threatening conditions (e.g., cancers) are usually cared for by their parents and extended families (Eaton, 2008). Given the burden of treatment and risk of death of the child, providing this care can be stressful and can put a strain on the children and their families (Yantzi et al., 2007). Palliative care services and hospices are designed to support and care for children with such illnesses and their families (The National Institute for Health and Care Excellence [NICE], 2016). The primary aim of palliative care services is to improve the quality of life of patients with life-limiting or threatening conditions and their families through the provision of holistic care, covering clinical, social, emotional and spiritual aspects of their needs (NICE, 2016). Multidisciplinary teams (e.g., nurses, social workers etc.) deliver palliative care services across different stages of the patient's illness (not necessarily just those terminally ill) in a host of settings, including hospices.

Hospices are free in the UK and focus on supporting those with terminal illnesses (but not exclusively at the end of their lives) through a range of services including respite care, pain and symptom management as well as bereavement support (Connor, 2017). Patients can access onsite hospice care as an outpatient (e.g., counselling) or inpatient (e.g., overnight respite stay), but can also be served in the community or in their home (Connor, 2017). In this study the focus is on both hospice and palliative care delivered in the community and onsite (as outpatient and inpatients), which will be referred to collectively as palliative care services.

Despite the benefits of palliative care services research shows that they are not accessed equally (Pearson et al., 2017), often due to demographic factors (Rosenwax et al., 2016). Several groups are less likely to use such services including older people (Nahapetyan et al., 2017), black and minority ethnic groups [BME] (Dixon et al., 2015), and those who are economically disadvantaged (Dixon et al., 2015).

A growing body of literature has identified various barriers to accessing hospice and palliative care and include issues surrounding referral practices, lack of knowledge and misperceptions of

these services (Nahapetyan et al., 2017). For instance, evidence suggests that referrals from hospital to hospice settings is lacking (Wentlandt et al., 2012), which can be explained in some instances by differences in understanding and appreciation of hospices and their services amongst professionals (Wentlandt et al., 2012). Families' lack of awareness and misperceptions of hospice and palliative care services serves as a barrier to access in some cases (Nahapetyan et al., 2017). For example, research shows that the use of hospice care can be perceived by some family members as giving up on the patient (Knapp & Thompson, 2012).

The available literature focuses primarily on adult palliative care services, raising questions as to whether these challenges are also applicable to similar children's services. This is underscored by the limited work on the barriers to accessing children's palliative care which suggests that this area faces significant deficiencies (Malcolm et al., 2008), is under recognised (Goldman, Hain, & Liben, 2012) and calls to explore the nature and specificity of children's needs in this area (Grinyer, Payne, & Barbarachild, 2010). Further research on this topic is warranted and timely.

To date, there has been only one study that has examined the barriers of paediatric palliative care in the UK from the perspective of health care professionals (Twamley et al., 2014). Findings from this study revealed that although health care professionals had a good understanding of the principles of palliative care, their attitudes and reported reasons for referral demonstrated an association of palliative care with death and dying (Twamley et al., 2014), which may explain referrals made at advance stages of the child's illness (Knapp, Madden & Fowler-Kerry, 2012). Despite the fact that many hospices in the UK provide services to support families throughout the illness not just at the end of their life (e.g., respite care) (Connor, 2017). The primary aim of this study is to explore palliative care professionals' perceptions of the barriers and challenges that prevent or delay families from using palliative care services in South East London, UK, directly responding to the identified need for research in this area (Grinyer, Payne, & Barbarachild, 2010). This study will extend previous research (Twamley et al., 2014) by focusing

on the perceptions of palliative rather than general health care professionals. The results of this work will make a novel contribution to the field since palliative care professionals' primary focus is to support families of children with life-limiting or threatening conditions and therefore have more exposure to and greater insight to the barriers to paediatric hospice and palliative care compared to their general health care counterparts.

Method

A qualitative content analysis design was used in the present study. Content analysis is a research method that seeks to reveal the content of data through the systematic classification process of coding and identifying themes or patterns (Downe-Wamboldt, 1992).

Setting

This study focused on the Southwark and Lewisham boroughs of London, UK, two areas in which an estimate of 30% of children live in poverty (Trust for London, 2015 ab), and 60% of the residents are from BME groups (ONS, 2011 ab). Residents of these boroughs have access to one local children's hospice service, as well as to various community-based and tertiary children's palliative care services.

Participants

The participants consisted of five palliative care professionals, working across tertiary and community-based services in the Southwark and Lewisham boroughs of London, UK. Participants were recruited through convenience sampling via email invitation. They all provided informed consent and were debriefed at the end of their interviews.

All participants were Caucasian women with a mean age of 44 years working in nursing or social work roles. Three of the five participants were involved in making referrals to children's hospice services (two worked in a children's hospital and one in a charity for children with life-limiting or threatening conditions) and the other two worked in a children's hospice. Overall, the participants had up to 20 years experience practicing in paediatric palliative care settings. The majority of participants had been practicing for 10-20 years (3 participants), with one participant having between 5-10 years experience, and the other between 0-5 years.

Data collection

Data was obtained via semi-structured interviews conducted by a Research Assistant [RA], who was trained up to Masters level in qualitative methods and interviewing. The interviews lasted 40-60 minutes and were audio-recorded. Interview questions (see Appendix I) focused on palliative care professionals' perceptions regarding (a) barriers that prevent or delay families from using palliative and hospice care services (e.g. 'In your experience, what are some of the most common barriers of families when accessing care?') and, (b) the families' expressed and observed challenges regarding access to palliative and hospice care for their children (e.g. 'Do you recognise any particular challenges that families with a child with a life-limiting or life-threatening condition may be facing when accessing services in the community?'). Given that the interviews were semi-structured the questions were not necessarily posed in the same order and additional questions were asked where needed. This study received ethical approval from the Department of Social, Therapeutic and Community Studies at Goldsmiths, University of London (reference: EA 1283).

Data analysis

From the three types of qualitative content analysis approaches (i.e., the conventional, the directed, and the summative) (Hsieh & Shannon, 2005), the conventional approach was chosen in the present study with the purpose of generating knowledge on the palliative care professionals' perceptions of the barriers and challenges of families who do or do not make use of hospice and palliative care services. According to Hsieh and Shannon (2005), a directed content analysis requires a strong body of research to describe and identify gaps in it; this approach would not benefit the purposes the current study given the paucity of research on this topic. A summative content analysis requires the researcher(s) to quantify terms and explore a phenomenon in a structured manner, which was not possible given the small sample size used in this investigation. Thus the conventional approach was most suited to this study (Vaismoradi, Turunen, & Bondas, 2013).

Initial data analysis by the RA was published in a report launched in February 2016 for the funders and interested stakeholders. The authors conducted further analysis of the data for the purposes of this paper, which included refining the themes and categories. Data was transcribed verbatim and anonymised by the RA, the transcripts were screened by another researchers (PP) for accuracy, and analysed using thematic analysis in NVivo (QSR International, 2015). The process involved familiarisation of the data through reading and re-reading of the transcripts; the researchers (the RA and PP) reviewed the transcripts individually as they emerged, and revisited them together once data collection was complete. The transcripts were then reviewed by GH and AJ for clarity and to confirm the identified themes. The data and themes were later audited by DP to increase the validity of the information. An indexing framework was derived from themes arising from the transcripts, which was used to organise the interview data. To ensure the trustworthiness of findings all the researchers discussed, clarified and reached consensus on the coding and analysis of data.

Results

Three themes emerged from the data and eight categories (Table 1). The first theme refers to the current availability and adequacy of palliative and hospice care in addressing the children's and families' needs; the second theme is concerned with the main barriers that interfere with or prevent the use of the services; the third theme is concerned with the role of cultural and family values/priorities in accessing children hospice and palliative care.

<Table 1 about here>

Availability and adequacy of palliative care for children

This theme focused on the professionals' perceptions of the availability and adequacy of paediatric palliative care services and is comprised of the following four categories.

Limited professional capacity in numbers and expertise

Professionals' perceptions in this category were broadly shared. There was a common understanding that teams responsible for the provision of palliative and hospice care for children are not fully resourced. Professionals recognised that there is inadequate specialist expertise (e.g., spiritual beliefs, contacts in other services or agencies) in those teams to appropriately respond to the complex needs of the family and the child.

> 'We use our own chaplains within the hospital. So we would – we would ask them about their – we always take that into consideration but we do not have so much training in these areas of spirituality'. (Participant 5)

> 'I used to refer all the oncology children to the hospice, especially the sibling support. You need to know those skills to liaise and make referrals' (Participant 4)

'It's about getting the right skill sets. We realised [when working] with this family that it wasn't our area of expertise'. (Participant 1)

Some participants shared accounts about occasions when the expectations (e.g., provision of social/emotional support) and needs (e.g., respite care, services at home and in the community) of the patient's family exceeded the organisation's resources and capacity to respond because of insufficient staff.

'So, the choices that we all thought we could give children, when the 'Better Care Better Lives' document was written, are not there anymore. So, parents feel quite disarmed, because they are at home, on their own, with a child who has got escalating pain, and there is not anybody who can come out and see them at a weekend. Or out of hours. Or to change a syringe driver'. (Participant 5)

'Sometimes it's expectations like practical and emotional support…so that was a…'this is not something we can do for you'. Which is obviously a big problem with lack of resources'. (Participant 3)

Unreliability of respite care

Respite care is one of the main services offered by children's hospices, but participants expressed concerns regarding limited local hospice capacity and cancellation policy of this service. Last minute cancellation of respite offers due to lack of resources and/or if another child requires end-of-life care was highlighted as particularly problematic.

'I think the only major negatives I have had from the families is the cancellations that [the hospice] obviously having [very few] beds, and having to prioritise. If they [the families] are counting on those nights, and they look forward to that because that is their respite, and you know, they look after their children, day in day out, 24 hours a day, and these children need monitoring closely…so it is really intense and…- I think this year has been really bad for cancellations. I think that I have had a lot of families who have had to rely heavily on social services' hours for support, because [the hospice] has obviously not had the capacity to have the child come and stay'. (Participant 3)

Insufficient psychosocial support

Participants felt strongly that the psychosocial aspects of hospice care and support have received scant attention. Cross-referencing with deprivation and poverty in South East London, participants reported that hospice care provision is medically-led and insufficient consideration is given to the psychosocial needs of the child and their family. The participants reported that social activities geared towards children with life-threatening or limiting conditions and families, were lacking.

'I think one thing maybe staff haven't done because it [services] was medically led, is actually recognise the risk and social aspects that are going on with families – needing more social support to come to terms with the child's illness'. (Participant 1)

'I think it is all social, I think it is just the getting them out and doing stuff. I think the health kind of things is pretty…you know, sorted in a lot of ways. I mean there is always

things to improve upon but…I think the social side of things, that is still developing.'

(Participant 3)

Further, professionals from this study reported that families express feelings of discomfort when being perceived as vulnerable in public, which, in turn, jeopardises their opportunities for community engagement.

'I hear it time and time again from families, where they feel uncomfortable going in public places, because people stare, people ask them questions, people comment, and they want to be somewhere with people that they do not feel that, they do not get that.'

(Participant 2)

Creating unrealistic expectations

Professionals reported that, palliative care services can become overwhelmed by a desire to help children and their families and intervene when possible, even if it is outside of their remit. It was reported that they often show a willingness to respond and accommodate to various needs of the child and family at any time necessary. The major challenge with this as identified by the study participants is that families become accustomed to this support and service and can become distressed when it is not available or it is withdrawn.

'I think some families you know…can ring and they can say "I'm really stressed, and I really need a break" and things are shifted around and they can come in [to the service]… they can do that once or twice, and then they get dependent on that, so when

they *can't* do it, it's really difficult for them to cope? Because that's almost been a learned coping strategy – "just ring us, anytime". (Participant 1)

'And a lot of parents have mental health, from anxiety disorder to depression, bipolar. So, [we] will be assessing the parents, because obviously they're a vulnerable adult as well, so making sure that we're giving safe care to everybody. Substance abuse is another one we're faced with, domestic violence, domestic abuse I should say, and….a lot of that is built up from the stresses in the family, you know, having a diagnosis of a child who's going to die young is….it wobbles people, to say the least. So we would get involved at that early stage, when a family are struggling to cope generally'. (Participant 2)

Obstacles to accessing and benefiting from palliative care

This theme focused on the participants' perceptions of the obstacles that prevent or delay families from accessing children's palliative care and include prejudices, misconceptions and stigma.

Negative perceptions of hospice care

All participants shared the view that some families are intimidated by the concept of 'hospice' and its association with end of life care and death. In these cases participant indicated that some families are fearful of admitting their child into a hospice and often interpret the referral as a covert message of the treatment's failure. Moreover, some parents fear the exposure to the illness and death of other children when in hospice care.

'There was talk [among team members] about taking the hospice word away. And I felt quite passionate about that, because I think it probably does put a lot of families off.' (Participant 4)

'And they [families], generally, are quite open about their fears of walking in that door, and how difficult it was, as a family to set foot in. As I said, with preconceptions about end of life and thinking this may happen to their child…it is difficult'. (Participant 2)

Finally, many hospices cater for children with various illnesses, which was reported to influence some families' perceptions of the relevance and usefulness of the service for them.

'But you put a cancer patient in a hospice where there are children who have got progressive neuro-degenerative illnesses, and it frightens them... If there is a large cohort of patients who are very different to their own child, it makes them feel like, "this is maybe, this is not for us".' (Participant 5)

Transportation challenges

One of the barriers most frequently raised by professionals relates to access to appropriate transportation to attend the closest onsite hospice service. While most hospitals provide transport options for families, this is not be possible for hospices. This is problematic particularly for families that lack the resources to afford such amenities. It has been estimated that approximately 40% of residents in this area of London do not have access to a car (ONS, 2011b). Public transport is unlikely to be a viable option due to the child's condition and need to carry multiple pieces of medical equipment, which can be bulky and heavy.

'Some of the families, if they do not drive, and they have got a child with a ventilator, and a suction machine, and a pushchair, and a SATS monitor, and a bag of all the spare stuff, you know getting down on the train is impossible.' (Participant 3)

Cultural values and family priorities

This theme highlights the cultural and familial factors that either present challenges or provide reasons why some families do not access paediatric palliative care and include the following two categories.

Cultural and religious resources in BME communities

Some professionals reported that some families belonging to non-western cultural groups may seek solace, comfort, and respite from their extended family or religious community. This may inform the decision not to access children's palliative care services.

'They have massive families, and well-supported, and so they often, in my experience, have wanted to stay at home.' (Participant 4)

In particular, participants indicated that from their experience many families from BME communities have strong and extensive social support systems, often linked to the church. This may mean, according to participants' views, that families do not seek palliative care since their needs are met through the support of their communities.

'And the religious side of things – lots of church communities come together and offer support –it's quite what – you know, very what we used to do in the old days before we had systems in place to support families. The church community, they've still got old traditional values, that are current in their culture. And also I think families coming together and I think…especially in….some of the African groups, there'll be people from the church who'll come in and provide care for the child.' (Participant 1)

Family values and priorities

Some participants described families persevered in achieving a cure, remained within the medical system and were open to using palliative care, even if these went against their religious beliefs.

'I think that people who have religious beliefs, whether it's Muslim, Christian, Jewish, you know…Jehovah's Witness, whatever! – I think their belief kind of almost…sometimes will go out of the window when it comes to their child, because they fight tooth and nail to keep that child alive, even when maybe it's not necessarily in line with their religion.' (Participant 3).

For other families their cultural beliefs or values contribute to their decision not to use hospice care services.

'We have noticed that culturally some families would struggle in giving over care to somebody else for their child, because in their culture it is seen that we look after our own children, and that…it's not for a stranger to do that sort of thing. [Families] feel like

they don't want to *burden* somebody else with their child and the child's illness'. (Participant 1)

Discussion

This preliminary study aimed to identify the perceived barriers and challenges to accessing inpatient paediatric hospice care in South East London, UK as described by palliative care professionals working with children with life-limiting or -threatening conditions. According to their accounts, several factors contribute to families' decisions to not seek palliative care for their children, these include misconceptions and biases of such care as well as receipt of support from community and religious groups. What also emerged from the data is that families wishing to use the services palliative care, particularly for onsite hospice services encounter numerous challenges and barriers, these include problems with transportation, limited capacity of palliative care services which may lead to unreliability of respite care. To summarise the results suggest two key issues, first, not all families are able to benefit from the services of palliative care due to factors that influence their initial decision to seek these services. Second there are factors impacting such services capacity for provision of care effectively, creating barriers for families wishing to use their services. Clearly there is an urgent need to address these issues.

In examining the data three broad themes emerged which will be discussed in turn. The first theme is concerned with the availability and capacity of children's hospice care comprised of four categories ranging from unreliability of respite care to insufficient social support. Limited resources may create unstable provision of respite care (e.g., last minute cancellations of respite offers) which may cause distress amongst service users (i.e. children and their families). This is of utmost importance considering that patient satisfaction is dependent on good relationships, rapport and trust with service providers (Bridges et al., 2013). This is congruent with the findings from the adult literature which shows that the reliability of a palliative care provision and the

personnel that run it impact on people's decision or motivation to access such services (Bray & Goodyear-Smith, 2013). Palliative care for children in South East London was reported by some participants to focus primarily on physical and medical needs of the patient, promoting a medical approach, which underserves the families' social and emotional needs.

The second theme concerned obstacles in accessing children's hospice care and included two categories: negative perceptions about such care and problems with transportation. Previous research shows that there is a pressing need for better awareness of adult hospice and palliative care in the community (Heller & Solomon, 2005). The results of the current study provide evidence that this needs to be extended to children's services (Hain, Heckford & McCulloch, 2012). Transportation for families with no access to a car or the financial capacity to cover the transport cost is a major obstacle when they wish to benefit from palliative services but lack the resources. This is especially pertinent to the families living in these two boroughs in London with relatively low car ownership or access (ONS, 2011ab). These findings are inline with previous research which identified transportation difficulties as a key factor that impacts patients' ability to access a number of health services including palliative care (Friedman et al., 2012).

The final theme centres on the role of cultural and family values in the decision to seek palliative care and consisted of two categories (cultural and religious resources in BME communities; and family values/priorities). Our findings provided some preliminary evidence that for some families their religious beliefs are set aside, when it comes to their child's care and treatment. Replication of this result is needed from larger studies focused on families not professionals before firm conclusions can be drawn. Given that previous research suggests that religious beliefs often inform families' decisions not to make use of hospice services, (Siden et al., 2008) the results of this study open a debate in this area. Further, and in accordance to this study, cultural groups provide resources and support that families and their children and draw on outside of hospice services.

Nevertheless, palliative care may not be the preference of all (Teno et al., 2004). According to the participants' experiences, some families seek support and care from other sources (e.g., religious/community group and/or family). Future research should explore in greater depth the experiences of BME families. Also, in light of the preference for death sites (Bekelman et al., 2016) some families prefer their child to be at home and be cared for by people with whom they have close relationships (Teno et al., 2004).

Although the current investigation is limited for several methodological reasons the results provide some insight into factors that play a role in a family's decision and ability to access hospice and palliative care in South East London, UK, which need to be brought to the attention of relevant service providers. For instance, solutions surrounding the transportation issues families face which prevent them from using hospice services must be sought and implemented. Furthermore, misperceptions about palliative care services need to be dispelled, one solution would be to implement an educational campaign through posters and better signposting by other professionals working with affected families. Such solutions promise to positively impact on the lives of affected children and their families.

Methodological limitations

This study focused on two boroughs of South East London, thus the findings cannot be generalised to all parts of the UK, although the results are most relevant to areas with residents from a similar demographic and socio-economic background. Another limitation of the current investigation is the restricted sample size of palliative care professionals who were recruited through convenience sampling, which may have biased the results. Thus the findings presented here are preliminary but should spark a dialogue among professionals and researchers concerning the issues raised and possible solutions to the barriers highlighted. The field would benefit from future studies that recruit a large number of palliative care professionals using random sampling

approaches. The perceived barriers to children's palliative care services were explored through the lens of palliative care professionals, which provides useful insight into the challenges that families encounter. However, the perceptions of palliative care professionals may not be accurate representations of the experiences of families with children with life-limiting or threatening conditions, for a number of reasons, including their own biases and missed information. Therefore the results of this study should be interpreted cautiously and any conclusions should be considered tentative. It would be valuable for future studies to extend this investigation and interview families with children with life-limiting or threatening conditions to understand the factors that influence their decision to use palliative care services.

Conclusions

This is one of the few studies to explore the potential barriers to accessing children's hospice and palliative care services. The results showed that palliative care professionals perceive a number of major barriers that prevent or delay families from accessing such services and include the families' negative perceptions about palliative care, transportation difficulties as well as lack of resources and expertise. However, the findings also highlight the significance of cultural and/or religious factors that may influence a family's choice of its support system, which may complement palliative and hospice services.

References

Bekelman, J. E., Halpern, S. D., Blankart, C. R., Bynum, J. P., Cohen, J., Fowler, R., ... & Oosterveld-Vlug, M. (2016). Comparison of site of death, health care utilization, and hospital expenditures for patients dying with cancer in 7 developed countries. *JAMA*, *315*(3), 272-283.

Bray, Y., & Goodyear-Smith, F. (2013). Patient and family perceptions of hospice services: 'I knew they weren't like hospitals'. *Journal of Primary Health Care*, 5(3), 206-213.

Bridges, J., Nicholson, C., Maben, J., Pope, C., Flatley, M., Wilkinson, C., ... & Tziggili, M. (2013). Capacity for care: meta-ethnography of acute care nurses' experiences of the nurse-patient relationship. *Journal of Advanced Nursing*, *69*(4), 760-772.

Cohen L.L. (2008). Racial/ethnic disparities in hospice care: a systematic review. *Journal of Palliative Medicine*, 11, 763-768.

Connor, S. (Ed.). (2018). *Hospice and palliative care: The Essential Guide (3ʳᵈ ed).* New York, NY: Routledge.

Dixon, J., King, D., Matosevic, T., Clark, M., & Knapp, M. (2015). Equity in the provision of palliative care in the UK: review of evidence. Retrieved from www.pssru.ac.uk/publication-details.php?id=4962

Downe-Wamboldt B. (1992). Content analysis: method, application and issues. *Health Care for Women International,* 13, 313-321.

Eaton, N. (2008). 'I don't know how we coped before': a study of respite care for child in the home and hospice. *Journal of Clinical Nursing*, 17(23), 3196-31204.

Friedman, S.L., Helm, D., & Woodman, A.C. (2012). Unique and universal barriers: Hospice care for aging adults with intellectual disability. *American Journal on Intellectual and Developmental Disabilities*, 117(6), 509-532.

Goldman, A., Hain, R., & Liben, S. (Eds.). (2012). *Oxford Textbook of Palliative Care for Children (2ⁿᵈ ed.).* New York, NY: Oxford University Press.

Grinyer, A., Payne, S., & Barbarachild, Z. (2010). Issues of power, control and choice in children's hospice respite care services: a qualitative study. *International Journal of Palliative Nursing*, *16*(10), 505-510.

Hain, R., Heckford., E. & McCulloch, R. (2012). Paediatric palliative medicine in the UK: past, present, future. Archives of Disease in Childhood, 97, 381-384.

Heller K.S. & Solomon M.Z. (2005). Initiative for Pediatric Palliative Care (IPPC) Investigator Team. Continuity of care and caring: what matters to parents of children with life-threatening conditions. *Journal of Pediatric Nursing*, 20, 335-346.

Hsieh H.-F. & Shannon S.E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15, 1277-1288.

Knapp, C., Madden, V. & Fowler-Kerry, S. (Eds). (2012). Pediatric Palliatve Care: Global Perspectives. Dordrecht, Netherlands: Springer

Knapp C. & Thompson L. (2012). Factors associated with perceived barriers to pediatric palliative care: a survey of pediatricians in Florida and California. *Palliative Medicine*, 26, 268-274.

Malcolm C., Forbat L., Knighting K., & Kearney, N. (2008). Exploring the experiences and perspectives of families using a children's hospice and professionals providing hospice care to identify future research priorities for children's hospice care. *Palliative Medicine*, 22, 921-928.

Nahapetyan, L., Orpinas, P., Glass, A., & Song, X. (2017). Planning Ahead: Using the Theory of Planned Behavior to Predict Older Adults' Intentions to Use Hospice if Faced With Terminal Illness. *Journal of Applied Gerontology*, https://doi.org/10.1177/0733464817690678

National Institute for Health and Care Excellence (2016). End of life care for infants, children and young people with life-limiting conditions: planning and management. NICE guideline (NG61)

NVivo qualitative data analysis Software; QSR International Pty Ltd. Version 11, 2015

ONS [Office for National Statistics]. (2011 a). *Neighbourhood Statistics: New Cross* (ward), https://www.neighbourhood.statistics.gov.uk/dissemination/LeadAreaSearch.do?a=7&i=1001&m=0&s=1453132908766&enc=1&areaSearchText=new+cross&areaSearchType=14&extendedList=false&searchAreas (Accessed 24 June 2016).

ONS [Office for National Statistics]. (2011 b). *Neighbourhood Statistics: Peckham* (ward), https://www.neighbourhood.statistics.gov.uk/dissemination/LeadSByASelectScotNI.do?a=7&c=peckham&d=14&i=1001x1002&m=0&r=1&s=1453135394453&enc=1&areaId=13689053&OAAreaId=6336933 (Accessed 29 June 2016).

Pearson, C., Verne, J., Wells, C., Polato, G.M., Higginson, I.J. & Gao, W. (2017). Measuring geographical accessibility to palliative and end of life (PEoLC) related facilities: a comparative study in an area with well-developed specialist palliative care (SPC) provision. *BMC Palliative Care*, *16*(1), 14.

Rosenwax, L., Spilsbury, K., McNamara, B.A., & Semmens, J. B. (2016). A retrospective population based cohort study of access to specialist palliative care in the last year of life: who is still missing out a decade on? *BMC Palliative Care*, *15*(1), 46.

Siden H., Miller M., Straatman L., Omesi, L., Tucker, T. & Collins, J.J. (2008). A report on location of death in paediatric palliative care between home, hospice and hospital. *Palliative Medicine*, 22, 831-834.

Teno J.M., Clarridge B.R., Casey V., Welch, L.C., Wetle, T., Shield, R. & Mor, V. (2004). Family perspectives on end-of-life care at the last place of care. *JAMA*, 291(1), 88-93.

Trust for London. (2015 a). *London's Poverty Profile: Lewisham,*

http://www.londonspovertyprofile.org.uk/indicators/boroughs/lewisham/ (Accessed 28 June 2016).

Trust for London. (2015 b). *London's Poverty Profile: Southwark,*

http://www.londonspovertyprofile.org.uk/indicators/boroughs/southwark/ (Accessed 28 June 2016).

Twamley K., Craig F., Kelly P., Hollowell D.R., Mendoza P. & Bluebond-Langner M. (2014). Underlying barriers to referral to paediatric palliative care services: knowledge and attitudes of health care professionals in a paediatric tertiary care centre in the United Kingdom. *Journal of Child Health Care*, 18, 19-30.

Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & Health Sciences*, *15*(3), 398-405.

Wentlandt, K., Krzyzanowska, M.K., Swami, N., Rodin, G.M., Le, L.W., Zimmermann, C. (2012). Referral practices of oncologists to specialized palliative care. Journal of clinical Oncology, 30(35), 4380-4386.

Yantzi N.M., Rosenberg M.W., & NcKeever P. (2007). Getting out of the house: challenges mothers face when their children have long-term special needs. *Health and Social Care in the Community*, 15, 45–55.

Appendix I Semi-structured Interview Guide – Questions

- Can you tell me a little about the services available in this organisation/ institution/ department, as well as your role in it?

- Who are some of the partners in the community that you work with, and when would referrals be made by your organisation/ institution/ department to other services or hospices?

- In your experience, what are some of the most common barriers of families when accessing care?

- Have you noticed whether ethnic cultural background is a factor in a family's choice about the type of care their child receives? If so, can you give me an example?

- If any, what are some of the challenges that families are facing when involved with hospice services?

- Do you recognise any particular challenges that families with a child with a life-limiting or life-threatening condition may be facing when accessing services in the community?

- Do you find that adequate training and opportunities for continuous development have been, and are, provided to professionals in this field?

- Is there anything else you would like to add? For example, if you had a message for the palliative care community, what would that be?