

Centre for Public Health Research

**Evaluation of the Paediatric
Home-based Palliative Care Service**

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Table of Contents

	Page number
Acknowledgements	i
Table of contents	ii
List of tables	iii
1 Introduction	1
2 The Paediatric Home-based Palliative Care Service	1
3 Methodology	2
4 Findings	3
4.1 Monitoring data provided by Claire House Children’s Hospice	4
4.2 The questionnaire	4
4.3 Interview findings	8
4.3.1 Aspects of support	8
4.3.1.1 Reassurance	8
4.3.1.2 Avoiding hospital	10
4.3.1.3 Practical support	12
4.3.1.4 Emotional support	13
4.3.1.5 Education	13
4.3.2 Characteristics of the service perceived as ‘good’	14
4.3.2.1 Giving advice and informality	14
4.3.2.2 Contact from service	14
4.3.2.3 Communication	15
4.3.2.4 ‘Exceeding the role’ and ‘going the extra mile’	15
4.3.3 Long term support	16
4.3.4 Caring at home	17
5 Discussion and conclusion	18
References	21
Appendices	
Appendix 1 Letter of invitation	22
Appendix 2 Participant information sheet	23
Appendix 3 Consent form	24
Appendix 4 Interview schedule	25
Appendix 5 Questionnaire	26
Appendix 6 List of comments from questionnaire	27

List of tables

	Page Number
Table 4.1.1 Total number of children registered with the Paediatric Home-based Palliative Care Service (year one and two)	4
Table 4.1.2 Total number of contacts with children, parents or siblings or other family members related to registered children	4
Table 4.2.1 Service users' rating of information received prior to first visit	5
Table 4.2.2 Service users' understanding of the service upon the initial visit	5
Table 4.2.3 Service users' rating of information regarding how to contact the service	6
Table 4.2.4 Service users' ratings of the frequency of contact with the service by telephone and home visit	6
Table 4.2.5 Service users' ratings of the content of contact with the service by telephone and home visit	7
Table 4.2.6 Extent to which the Paediatric Home-based Palliative Care Service covered the needs of service users	8

Evaluation of the Paediatric Home-based Palliative Care Service

1. Introduction

Palliative care has been recognised as a medical speciality since 1987 (Hynson & Sawyer, 2001). However, it remains relatively underdeveloped in the paediatric setting, and there has been little research carried out in the area. One reason for this may be the nature and challenge of surveying caretakers about a highly emotive and painful subject (Hynson & Sawyer, 2001). However, as Dangel, Fowler-Kerry, Karwacki, and Bereda (2000) suggest, ongoing programme evaluation is a necessary component to improve the quality of service delivery. Research is required in all aspects of palliative care in order to ensure that this relatively new speciality can move forward from an anecdotal basis to one that has a sound evidence base (Twycross & Dunn, 1994).

The most distinctive feature of palliative care is its divergence from most other types of medical care: the aims are different to that of curative care and thus create different priorities. Palliative care focuses on relieving pain or the symptoms of a disease or disorder without effecting a cure (World Health Organisation [WHO], 2005). As such palliative care aims to preserve normality as far as possible; for the great majority of children and young people, this means delivering care in the home (Watterson & Hain, 2003). In this setting, parents play a key role in decision making as they are involved in the day-to-day management of their child's symptoms (Dangel et al., 2000).

2. The Paediatric Home-based Palliative Care Service

The Paediatric Home-based Palliative Care Service was initiated in September 2003 and aims to provide high quality care for children and young people with life limiting/threatening conditions and their families across Wirral and West Cheshire. It focuses on quality of life for the child, respite for the family, the management of distressing symptoms and support through death and bereavement. The objectives of the service are to:

- provide symptom management in palliative and terminal care;
- provide education for families and health care professionals in the field of paediatric palliative care;
- provide bereavement support.

A number of partners are involved in the delivery of the service, these are: Claire House Children's Hospice; Countess of Chester Hospital; Alder Hey Hospital; and Crossroads Caring for Carers. The service is delivered by a multi-disciplinary team including nurse specialists, children's nurses, health care assistants, physiotherapists, paediatric palliative care consultants and play and music specialists. It has been funded by a three year grant from the New Opportunities Fund (NOF) which is now the Big Lottery Fund. This funding has in part enabled the addition of 4.3 Full Time Equivalent (FTE) posts for the purpose of the Paediatric Home-based Palliative Care Service. These posts break down as follows:

- 2 x 1.0 FTE Registered Sick Children's Nurses for Claire House Children's Hospice;
- 2 x 0.5 FTE Health Care Assistant's for Crossroads Caring for Carers;
- 1 x 0.8 FTE Community Children's Nurse for Countess of Chester Hospital;
- 2 x 0.25 FTE Palliative Care Nurse Specialists for Alder Hey Children's Hospital, Liverpool.

The Centre for Public Health Research (CPHR), University of Chester, was commissioned to carry out this study, the purpose of which was to evaluate the extent to which the service is meeting its own aim and objectives from the perspectives of families who have accessed the service. The purpose of this report is to:

- describe service activity;
- examine quantitative data for those who have accessed the service;
- present the views of families who have accessed the service.

3. Methodology

All parents/carers who were currently accessing the service, or had accessed the service in the past, were invited by letter (Appendix 1) to take part in the evaluation study. Letters to parents/carers were distributed by the Paediatric Home-based Palliative Care Service in order that the researchers had no sight of individuals' names and addresses. A participant information sheet (Appendix 2) was included with the letter to provide detail of what would be involved for parents/carers taking part in the study. The participant information sheet had a tear-off slip for parents/carers who wished to take part, to provide contact details and return directly to the CPHR in a pre-paid envelope. Participants were then contacted by telephone by the researcher to arrange a suitable time and place for the interview to take place.

Participants were asked to sign a consent form (Appendix 3) prior to the interview taking place.

A series of 10 semi-structured interviews were carried out with parents and carers who had accessed the Paediatric Home-based Palliative Care Service, nine in participants' homes and one at CPHR, University of Chester. Semi-structured interviews have a 'loose' structure consisting of open-ended questions that define the area to be explored, but allow the interviewer or interviewee to diverge in order to follow up particular areas in more detail (Britten, 1995). Thus, although the interview topics and questions that lead into exploring these areas had been defined initially, the semi-structured format allowed interviewees to express ideas that are important to them, and also meant that answers could be clarified and more complex issues probed than would have been possible using a more structured approach (Bowling, 2002). With the permission of the interviewees all interviews were audio-taped, tapes were transcribed and the transcripts subjected to thematic analysis. A copy of the interview schedule can be found in Appendix 4.

Data collected from the semi-structured interviews were supplemented by data obtained from the parent satisfaction questionnaire that was developed by the Paediatric Home-based Palliative Care team. Fifty questionnaires were distributed by the Paediatric Home-based Palliative Care team to parents/carers who were currently accessing the service, or had accessed the service in the past, and returned directly to the CPHR in a pre-paid envelope. A copy of the questionnaire can be found in Appendix 5. Monitoring data provided by Claire House Children's Hospice has also been included in the report to show the numbers of children registered with the Paediatric Home-based Palliative Care Service, and the subsequent number of contacts that this generated.

The ethical issues inherent in this project were considered and scrutinised by Cheshire North and West Research Ethics Committee. The committee approved the study in August 2005.

4. Findings

This section will present the findings of the study in relation to:

- monitoring data provided by Claire House Children's Hospice;
- quantitative survey data collected from service users;
- interviews conducted with parents/carers who had accessed the service.

4.1 Monitoring data provided by Claire House Children's Hospice

Table 4.1.1 shows the total number of children registered with the Paediatric Home-based Palliative Care Service. It shows that in the first year there were a total of 23 children registered with the service which, in the second year, increased to 24 children. However, these numbers do not include parents, siblings and other family members related to registered children who are also in contact with the service. In the second year, the number of recorded family members associated with 24 registered children was 111.

Table 4.1.1 Total number of children registered with the Paediatric Home-based Palliative Care Service (year one and two)

	Number of registered children
Year 1	23
Year 2	24

Table 4.1.2 shows the total number of contacts (telephone, face to face and written) that the Paediatric Home-based Palliative Care Service had with either children, parents, siblings or other family members related to registered children. It shows that from 1 July 2003 – 30 June 2004, there were 255 telephone contacts, 153 face to face contacts and 2 written forms of contact. The total number of contacts was 410. Table 4.1.2 also shows that from 1 August 2004 – 31 July 2005 all forms of contacts increased. Telephone contacts increased from 255 to 261, face to face contacts increased from 153 to 643 and written contacts increased from 2 to 11. The total number of contacts increased from 410 to 915 (a total percentage increase of 123%).

Table 4.1.2 Total number of contacts with children, parents or siblings or other family members related to registered children

	Contacts		
	Telephone	Face to face	Written
1 Jul 2003 - 30 Jun 2004	255	153	2
1 Aug 2004 - 31 Jul 2005	261	643	11

4.2 The questionnaire

Of the 50 questionnaires distributed to parents/carers who had accessed the service, 12 completed questionnaires were returned to the Centre for Public Health Research for analysis, an overall response rate of 24%. It may be difficult to generalise from the sample due to its relatively small size, however, the findings presented here

should still be considered as valid views and opinions of service users. Percentages may not equal 100 due to rounding.

Service users were also invited to add their own comments where appropriate and some of these have been included in the report to reflect the views and experiences of service users. These are identified by a respondent number to ensure service user anonymity. A full list of comments made can be found in Appendix 6.

Table 4.2.1 shows how service users rated the information provided by the Paediatric Home-based Palliative Care Service prior to any home visits. It shows that 11 service users (92%) rated this information as 'excellent' while one (8%) rated it as 'good'.

Table 4.2.1 Service users' rating of information received prior to first visit

	No	(%)
Excellent	11	92
Good	1	8
Satisfactory	0	0
Poor	0	0
Total	12	100

Table 4.2.2 shows whether or not service users understood the purpose of the service, and how the service was able to provide assistance to them and their families, upon the initial visit. It shows that 11 service users (92%) stated they 'understood' the purpose of the service while one service user (8%) stated they were 'unsure of the details'. No service users stated that they 'did not understand'.

Table 4.2.2 Service users' understanding of the service upon the initial visit

	No	(%)
Understood	11	92
Unsure of details	1	8
Did not understand	0	0
Total	12	100

Table 4.2.3 shows service users' rating of the information they were given regarding how to contact the Paediatric Home-based Palliative Care team. It shows that 11 service users (92%) stated the information they were given was 'excellent' and one service user stated it was 'good'. No service users stated it was 'satisfactory' or 'poor'.

Table 4.2.3 Service users' rating of information regarding how to contact the service

	No	(%)
Excellent	11	92
Good	1	8
Satisfactory	0	0
Poor	0	0
Total	12	100

Table 4.2.4 shows service users' ratings of the frequency of contact with the service by telephone and by home visit. It shows that nine service users (75%) stated the frequency of contact by telephone was 'excellent' and three (25%) stated that it was 'good'. It also shows that 10 service users (83%) stated that the frequency of contact with the service by home visit was 'excellent' and two (17%) stated that it was 'good'. No service users stated that the frequency of contact by telephone or home visit was 'satisfactory' or 'poor'.

Table 4.2.4 Service users' ratings of the frequency of contact with the service by telephone and home visit

	Telephone		Home Visit	
	No	(%)	No	(%)
Excellent	9	75	10	83
Good	3	25	2	17
Satisfactory	0	0	0	0
Poor	0	0	0	0
Total	12	100	12	100

Table 4.2.5 shows service users' ratings of the content and value of contact with the service by telephone and by home visit. It shows that 10 service users (83%) stated that the content of contact by telephone was 'excellent' while two stated that it was 'good'. It also shows that 11 service users (92%) stated that the content of contact by home visit was 'excellent' while one stated that it was 'good'. No service users stated that the content of either telephone contact or contact by home visit was 'satisfactory' or 'poor'.

Table 4.2.5 Service users' ratings of the content of contact with the service by telephone and home visit

	Telephone		Home Visit	
	No	(%)	No	(%)
Excellent	10	83	11	92
Good	2	17	1	8
Satisfactory	0	0	0	0
Poor	0	0	0	0
Total	12	100	12	100

Reflecting on the contact they had had with the service, one service user commented:

'Several times I have contacted the nurse for various reasons; honestly, this has been a lifeline for me in emergency situations.' (R11).

All service users (12, 100%) rated the support offered by the Paediatric Home-based Palliative Care Service as 'excellent'.

To illustrate how the service had been able to support them in caring for their child, one service user made the following comment:

'On leaving Alder Hey [hospital], I was given no instructions how to deal with my child's gastrostomy - the nurses [from the Paediatric Home-based Palliative Care Service] came out the next day to explain and made daily visits to assist me in cleaning and dressing my child.' (R11).

Table 4.2.6 shows service users' responses when asked to what extent the Paediatric Home-based Palliative Care Service had covered their needs. Service users were asked to respond using a scale of one (poor) to six (excellent). It shows that seven service users (58%) rated the extent to which the Paediatric Home-based Palliative Care Service had covered their needs as 'six', four service users (33%) rated this as 'five' and one rated this as 'two'. However, the rating of 'two' provided by one service user was not congruent with the previous questions, in which the service user gave positive responses. It is unclear as to why the service user gave a comparatively low rating for this question, but it may be that the service user erroneously thought that the scale was in the reverse order, with one being 'excellent' and six being 'poor'.

The situation was slightly different for parents who derived their support from the community nurse team. As the community nurse team were not available at weekends and overnight periods, if parents needed support during these times their option was to ring the hospital ward and if necessary, make the trip into hospital by themselves. One parent commented:

'My first port of call was always the community team and then if it was the weekend, it would be Chester [hospital]...if it was 2.00 am or something...I would ring Chester [hospital].' (No.9).

As well as this kind of 'hidden' reassurance, several parents explained that they were also able to access a more practical type of reassurance, to help them in moments of crisis or self-doubt. Parents described how particularly stressful times could induce a feeling of insecurity with regard to their ability as a parent (and carer) to make the correct decisions about what action to take. The facility to be able to speak to someone, and consult with that person, gave parents confidence in themselves and their own abilities to care, and enabled them to continue without progressing into a state of panic. In relation to this one parent said the following:

'...you do get times when you think, actually do I know what I am doing? Am I doing the right thing because I am not medically trained...and then to be able to pick up the phone and say, I don't know whether I am doing this right, could somebody just come out and check it over or check [child] over or check that I am doing this right? And to have somebody come in and say, [parent] that's fine. You then find that grounding again that you had before you lost it, and you think, yes actually I do know what I am doing and I am capable of doing this.' (No.1).

Parents also said that dealing with someone who was known personally to them, and was familiar with all of the family, their circumstances and the condition that their child was living with was important. Parents described how it was reassuring to talk to someone who knew all about 'their case' and had some history of dealing with them, and experience of dealing with, in some cases, quite rare conditions. This resulted in parents feeling assured that any advice given would be based on historical context as well as the individual circumstance and medical knowledge. It also meant that the service was often their 'first port of call' (No.3). A parent describing why this was the case said the following:

'They know you, they see you every week, they know the child, they just know.' (No.6).

Another major form of reassurance discussed by parents stemmed from the service effectively *'taking the strain'* (No.2) for parents. By making arrangements on behalf of parents who felt unable to do so (because of the stressful nature of what they were going through), parents described how they were then able to focus on more important things, such as spending time with their child. Not having to worry about organising or making arrangements was a weight off parents' minds which helped them reduce stress levels and remain calm. One parent reported the following:

'So they were taking care of all of that side of things, like they sorted out a chest X-ray at home, they got on the phone to my GP and explained...they were there for me to like say, what do I do now, who do I turn to now and they would contact all the necessary people, physios, they would speak to my doctor because they knew exactly how to properly word it better than me really in my way, and obviously I was very stressed.' (No.2).

4.3.1.2 Avoiding hospital

While acknowledging that in some instances admission to hospital is unavoidable and the most appropriate action to take, several parents who took part in the study stated that a major benefit of using the Paediatric Home-based Palliative Care Service was being able to spend as much time as possible away from the hospital. Parents described a number of advantages for themselves, their children and also the family as a whole. One of parents' primary concerns was how their child felt about going into hospital. Parents explained that children strongly disliked going to hospital and often became severely distressed at the prospect of attending. Parents described how the process of going to hospital was extremely disrupting to home life and therefore it was a constant ideal to keep this to a minimum. One parent made the following comment:

'Even if you go just one day and one night at the hospital, it is so disrupting and that had more effect on [child], it had much more of a profound effect on him. He hated it, the hospital and he was always distressed. So the hospice to home service kind of avoided that, and you were only going to the hospital when you absolutely had no choice.' (No.1).

Another advantage of having medical treatment at home as opposed to attending hospital was that it decreased the amount of time that parents and children *'wasted waiting around'* (No.10). In some cases parents described how they could *'spend all day'* (No.10) at the hospital, as they saw it, unnecessarily. Treatment at home prevented this and meant that children would be much more comfortable, and less

anxious, in their own environment surrounded by familiarity and toys and so on. One parent commented:

'There's often a lot of waiting around [in hospital] even if it's just a simple you know 5 minute flush through his line or something. If they can do it at home you don't have to wait, they come, they do it and then they go.' (No.6).

Parents were also of the opinion that more time spent at home would help improve the 'recovery process', more so than staying in the hospital environment. Parents explained that children were happier at home, and this was reflected in how quickly children would begin to 'feel better' within themselves. One parent stated the following:

'Off the ward she's in an environment her body knows...it does make a difference.' (No.9).

In some instances using the home-based palliative care service made caring for other children easier. Parents with more than one child explained that *'transporting the whole family to hospital'* (No.8) was highly stressful for both parents and children, and having treatment at home alleviated this stress. Parents were able to stay with one child whilst the other was happy to play quietly or watch television and so on. One parent made the following comment:

'...you see I have got another, well at that time she was three and a half old daughter. We don't have any family up here. We had only just moved up here. So she [nurse] knew it was very difficult for us and would come out to us which made it better for [daughter].' (No.8).

Parents also suggested that avoiding the hospital environment as much as possible also helped to maintain an atmosphere of 'normality', and that this was beneficial for all the family. In relation to this one parent made the following comment:

'You have got to try, as difficult as it was, to try and lead as normal life as possible and with as little intrusion as possible and that is why [nurse] used to come out to the house rather than having to take [son] to hospital because he was seeing enough of those and I think [nurse] felt and we all felt, that as little intrusion we could get away with would be better for all the family. Not just for [son] but for my daughter and us as well.' (No.8).

In some cases parents felt that they were getting a 'better' service than they would from a hospital setting. Some parents felt strongly that the level of expertise was far greater among staff from the Paediatric Home-based Palliative Care Service because staff were *'dealing with these kinds of conditions all the time'* (No.2). Some parents

therefore had greater trust in staff from the Paediatric Home-based Palliative Care Service and felt that their children were in safer hands. One parent commented:

'They just haven't got a clue in the hospital. I am sorry to say but they are really behind the door on that.' (No.2).

A concern also voiced by parents was that being in a hospital environment was dangerous for children as it exposed them to potential infection. Parents were therefore very mindful of trying to minimise this 'risk' as much as possible, particularly if treatments that children were having resulted in suppressed immunity, such as chemotherapy. Explaining this one parent said the following:

'So we would be admitted to the ward and again you've got the fear of, although you are in an isolation room, hospitals are not a good place to be if you are immune suppressed. So as soon as you could get home was the most important thing really.' (No.10).

4.3.1.3 Practical support

Practical support, although relatively simple, was an area where parents said that they highly valued support. In the instance illustrated below this was particularly helpful because the parent (a single father) was concerned about being physically invasive regarding his daughters needs.

'I mean for us it's mainly been looking after [daughters] personal needs because they arrange through, they arranged initially through Crossroads, that somebody would come in to sort [daughter] after she came home from school. So they would change her and freshen her up when she came home from school.' (No.3).

The practicalities of going from one place to another were not always straight forward, especially for single parents, and this was an area that parents were glad to receive help in. One parent stated:

'When we've been going to sort of consultant appointments, on several occasions somebody from hospice to home has come with us.' (No.3).

Physical treatments such as physiotherapy were provided at home in a number of cases to avoid having to transfer from one place to another.

One of some parents' major concerns was that they may be neglecting their other children due to their responsibilities as a carer. Parents perceived that with the practical support they were able to get through the Paediatric Home-based Palliative

Care Service, who could take over the care of their child for a short while, this was minimised. Explaining this one parent said the following:

'When [son] was ill, it was like, [daughter] had to take a backseat then you see because I couldn't do that many different things. So that is why Claire House comes in and help...I have got a bit of quality time with [daughter] to spoil her and give her a bit of me.' (No.2).

4.3.1.4 Emotional support

As well as the practical aspects of caring that parents were able to get support for, another major component of support that parents discussed was emotional and mental health support. This was for parents, children, siblings and extended family members.

A variety of examples of the emotional support that parents received were given. Some parents received massages to help with stress, parents had access to a family support worker who was *'ultimately there for the parents as opposed to the child'* (No.1), parents accessed counselling services with their children and in some cases counselling services were used by siblings of those children who were receiving care. Parents described how this provided a network of emotional support that they themselves, and other family members, could access to help them cope better with the realities of living with a life limiting condition and caring at home. One parent stated:

'I've got an appointment with the consultant next week, I don't know what that's going to bring. And if it's not good news I have no hesitation in phoning up and speaking to [counsellor] and saying I need a chat, I need to talk this through.' (No.4).

4.3.1.5 Education

During the interviews parents also talked about how they were able to gain more knowledge about how to care at home as a result of visits from the service. In some instances parents had been given advice regarding specialist equipment that may help them in their role as a carer. This gave them more self-confidence in their own abilities to care, as parents felt they were becoming more educated in caring techniques. One parent said the following:

'She [nurse] came out because he was complaining of very much pain in his hip at one point in time, and we just couldn't get to the bottom of it...she spent half an hour with us, told us how to position him a bit better in bed because he spent a lot of time in bed at that time...and his hips and his other joints were just getting stiff which was giving him a lot of pain.' (No.5).

4.3.2 Characteristics of the service perceived as ‘good’

Parents identified a number of characteristics of the service which they perceived were ‘good’ and discussed how this led to the support provided being appropriate for their specific needs. These are explored below.

4.3.2.1 Giving advice and informality

Parents described the service as working in conjunction with them, none of the parents felt that staff from the service were ‘telling you what to do’ (No.1). This created an informal relationship between parents and carers from the service, which parents explained led to an overall good working relationship in which trust and openness were crucial elements. One parent commented:

‘They treated us as human beings and they were human beings. We got to know [nurse] very well and she became quite a good friend so it wasn’t all clinical and the nurses were fantastic...and I think having them come out to your home and (a) they can see where you live and how you live and it is not just in a ward or something. They actually see you and they get to know you as a family which I think has got to be a good thing.’ (No.8).

Parents reported forming a good rapport with the Paediatric Home-based Palliative Care team due to the informal nature of the relationship and described how they became ‘friends’. This had led to some parents being able to set up a support group among themselves which was in part arranged by the community nurses.

4.3.2.2 Contact from service

Another characteristic of the service that was perceived by parents to make it high quality was the way in which members of the service team were very pro-active about contacting parents and families. Parents greatly appreciated being contacted by the service, as opposed to having to contact the service themselves. Parents were therefore in constant contact with the service both during periods of ‘good health’ and periods of crisis or serious illness. Consequently parents were able to build a much greater rapport with service staff which was beneficial, particularly during periods of greater need. The simple act of someone telephoning, or even popping round to see how they were was of great comfort to parents, which reinforced for many, that help was available should they need it. One parent made the following comment:

‘And it is the touches like that when you just think, actually they are worth more than their weight in gold these people. They kind of reach out to people when they have no need to

but they did and they were there...actually that is outstanding.’ (No.1).

4.3.2.3 Communication

All parents stated that communication with the service was easy, efficient and wherever call backs were required, there was very little delay. Several parents commented on the efficiency of the service and the speed at which support was available. Parents felt that this meant they were able to rely on the service. One parent commented:

‘Yes it was very late at night. I said I would phone back if I need to, but if you could come out first thing in the morning I would be grateful. And they did, which was great.’ (No.4).

Parents also explained how the Paediatric Home-based Palliative Care Service would take on the role of ‘central liaison’ on their behalf. Parents described how, in periods of crisis, the service acted as a type of ‘hub of intelligence’ which both alleviated responsibility (and consequently stress) for parents, as well enabling events to happen smoothly and efficiently. Describing this, one parent stated the following:

‘So all along, and particularly when we hit the major, major crisis the liaison between all the different people involved was ultimately linked around the hospice to home team which saved me because normally you wouldn’t get that. You wouldn’t get this central body saying, right I will take this on board and I will make sure that that person, that person and that person all know what is going on and ultimately were the centre point and that is really important. When you are going through a time like that it is really important and makes you feel a lot more confident with dealing with what you are dealing with as opposed to, what do I do, I have got all these people around me and none of them are talking to each other. Whereas they did the core of the communication.’ (No.1).

4.3.2.4 ‘Exceeding the role’ and ‘going the extra mile’

Parents gained comfort in the fact that they felt all staff affiliated with the Paediatric Home-based Palliative Care Service would do their utmost to help them. Many held the opinion that staff were prepared to go beyond the capacity of their role within the team and were dedicated to supporting parents who were caring for their children. Parents described how they thought members of the team ‘*exceeded their role*’ (No.7). Parents believed they could rely on the service because staff were ‘*prepared to go the extra mile*’ (No.1) for them.

For example, parents explained how community nurses took on extra responsibilities. In two cases parents explained that the community nurse had liaised with the local school. This was in order to explain life limiting conditions to the staff and emphasise that parents needed to be informed of any illness circulating round the school, as this could be particularly dangerous for a child with suppressed immunity. In another family, a parent described how a member of the service gave her a personal phone number. She stated:

'I mean she gave me her phone number and I could ring her, I could ring her any time. I mean obviously at weekends she's off but I know, I just know that she would have helped me out there if I had needed it. And I did ring...' (No.7).

4.3.3 Long term support

Another theme that emerged from the interviews was the need for long term support, particularly in cases of bereavement, but also in circumstances where children were post-treatment, for example after chemotherapy. This was an area where parents reported differing experiences.

Parents accessing services through Claire House described how they had, and continue to have, constant and ongoing support to help them cope with bereavement. A number of parents discussed how they were *'not forgotten about'* (No.1) after their child had died and felt reassured that if they felt they needed support, at any time, it was available to them.

'After days had gone by and I had lost [son], they had then come out again to see me and I had some counselling there as well...so they are still there and they still care.' (No.2).

As well as this, parents reported that support was proactively offered, in the form of a phone call or letter, rather than parents been required to actively seek it themselves. This was very important to parents, as some parents explained how they were not able to seek help for themselves. One parent commented:

'If you feel down you don't want to go and see the doctor, you don't want to go outside the front door.' (No.7).

This experience was different for parents who had had support from the community nurse team. A number of parents felt that after bereavement, or post-treatment, all the support they had been receiving came to an abrupt stop, and they explained that they found this extremely difficult to cope with. One parent commented:

'I struggled hugely after it had all finished. I kept going and kept going and then suddenly I wasn't being told to come into

hospital. For the last nine months our lives had been mapped out and suddenly it all stopped and I very much struggled.' (No.8).

Parents who had experienced this loss of support also stated that, in hindsight, they would have benefited from support after bereavement. One parent made the following statement:

'I think if somebody had come and knocked on the door or phoned me I would have actually welcomed them, do you know what I mean.' (No.7).

Parents described that there was some level of 'aftercare', but that this was often at the discretion of the community nurse, and something that was done outside of official work hours. In one case for example, the parent would see the community nurse during the nurse's lunch break. In other cases, community nurses would telephone on an ad hoc basis to see how parents were coping. However, the general feeling among parents accessing support via community nurses was that aftercare was something that could be improved upon.

4.3.4 Caring at home

Parents' experience of caring at home, for the most part, was centred on balancing work, care and family life. Many, particularly single parents, found it to be isolating and limiting in terms of both being able to work and having contact with others. Having the support of home care reduced this feeling and enabled parents to share their feelings of anxiety or frustration.

Overall, parents had an overwhelmingly positive view of home-based care, parents felt that it had many advantages and despite some feelings of frustration or hardship, believed that it was the best place for their child to be. Summing this up one parent made the following comment:

'I mean, it's just so nice to be at home. The more you can be at home the better.' (No.6).

All parents found it difficult to be critical of the services they had accessed. One issue that was raised by several parents was related to resources. Parents believed that the service should be available to all parents, not just those in the local area, as they thought that the service could help other parents in similar circumstances.

'I think it should be twice as big at least and it should have more... be able to do a lot more. You know that's in an ideal world.' (No.5).

5. Discussion and conclusion

This was a small scale explorative study that set out to evaluate the extent to which the Paediatric Home-based Palliative Care Service is meeting its own aim and objectives from the perspectives of families who have accessed the service. The findings describe service activity and present the perspectives of various families. It is evident from both the questionnaire and the interview data that parents' experience of the service was very positive. Through providing medical, practical and emotional support to parents and other carers, siblings and the extended family, the service enabled families to care for their child at home.

It is evident that the service is broadly meeting the aim and objectives that were set out at the beginning of the project. The increase in the number of contacts observed in the second year of the service may be indicative of the needs of those related or associated with registered children being met by the service. The findings show that the service has provided symptom management support for parents caring for children at home; it has provided education for families in the field of paediatric palliative care; and although some variation was noted dependent on how parents gained access to the service, for a number of parents the service was able to provide ongoing bereavement support. Given the importance of this aspect of service provision to parents, it is worth noting that one parent strongly believed they would have benefited from longer term bereavement support and follow up.

There were a number of ways in which parents and carers described that the service was able to support them: through giving reassurance; with practical and emotional support; through education; and by helping them avoid the need to take their child to hospital. In many cases this support stemmed from, and was underpinned by, the relationship and rapport that developed between parents and staff from the Paediatric Home-based Palliative Care team. Relationships of trust were built up and parents felt that they could be open towards staff and that this was reciprocated. This meant, for example, that in times of emergency or crisis the service was able to offer support by taking on the role of 'manager' in terms of ensuring that all relevant departments or organisations were made aware of changes, and mobilised if necessary. This was evidently very important to parents or carers who were inevitably under pressure and less familiar with the workings of the 'system' than members of the service team.

Also evident in the findings was the importance of service providers being pro-active in their care provision. Telephoning to see how families were getting on and telephoning after bereavement to offer support were identified by parents as being particularly valuable. In these cases it may be that relatively simple acts (such as a quick telephone call) were able to 'make a difference' and provide support for parents at a time when they did not have the resources within themselves to 'do the running' and request help.

Overall, parents perceived that care at home, wherever possible, was preferable to other alternatives. Families wanted to be at home for a number of reasons: it helped them maintain a sense of normality; children preferred being in familiar surroundings; it was better for the whole family and reduced stress and anxiety levels; parents perceived that children were able to recover or return to normal more quickly; and staying away from hospital meant that parents did not worry that children would pick up further infections from spending time in hospital. Understanding the support mechanisms that need to be in place for home care to be a possibility for both families and service providers is crucial for service development. While it may be the case that 'home care is best', it is clear from the findings of this study that this needs to be accompanied by support that can provide reassurance for parents and families, a 24 hour point of contact, home visits, and aftercare support. In this sense the findings of the study indicate the need for holistic family care.

Differences in access to services were apparent between those who had accessed home based services via Claire House and those who were receiving support from the community nurse team. Most notably, parents perceived that aftercare (either post-treatment or bereavement) was left to the discretion of the community nurse team and was dependent on their other commitments, therefore experience of this was somewhat varied.

This report has provided a description of the Paediatric Home-based Palliative Care Service and analysed data about service usage. The report has also outlined the key benefits to service users. It is evident that the Paediatric Home-based Palliative Care Service is a model of service provision that was able to meet many of the needs of families caring for children with life limiting conditions. Parents were enthusiastic about the service and considered that it should be standard care, not just available to those in a particular location due to the setting up of a specific project. Parents found it difficult to find fault with the service they received; where they did, the Paediatric

Palliative Care Service may be able to address these issues. However, parents' descriptions of aspects of the service that they found helpful and that made it, for them, a quality service can also be used to inform future decisions about service development.

References

- Bowling, A. (2002). *Research Methods in Health. Investigating Health and Health Services*. (2nd ed.). Buckingham: Open University Press.
- Britten, N. (1995). Qualitative interviews in medical research. *British Medical Journal*, 311, 251-253.
- Dangel, T., Fowler-Kerry, S., Karwacki, M., & Bereda, J. (2000). An evaluation of a home palliative care programme for children. *Ambulatory Child Health*, 6, 101-114.
- Hynson, J.L., & Sawyer, S.M. (2001). Paediatric palliative care: distinctive needs and emerging issues. *Journal of Paediatrics and Child Health*, 37, 323-325.
- Tywcross, R., & Dunn, V. (1994). Research in palliative care: the pursuit of reliable knowledge. Occasional paper 5. *National Council for Hospice and Specialist Palliative Care Services*. London.
- Watterson, G., & Hain, D.W. (2003). Palliative care: moving forward. *Current Paediatrics*, 13, 221-225.
- World Health Organisation. (2005). *WHO definition of palliative care*. Retrieved December 8, 2002, from <http://www.who.int/cancer/palliative/definition/en/>

Appendix 1
Letter of invitation

Date

Dear Parent,

The Centre for Public Health Research (CPHR), University College Chester would like to invite you to take part in a research study. The purpose of the study is to obtain your views and experiences of the Paediatric Home-based Palliative Care Service or the children's community nursing service. The study aims to use your views and experiences to evaluate the service. The service providers have asked the CPHR to carry this research out, and they have forwarded this letter to you on our behalf.

Your part in the study would involve taking part in an informal interview with a researcher to talk about your views of the services that you have received. There is no obligation to take part in the research study and if you feel unable to take part at the present time, please do not feel under any pressure to do so. However, if you would like the opportunity to express your views and experience of the home-based palliative care service, please fill in and return the 'consent to be contacted' slip, using the freepost envelope enclosed with this letter.

Once this has been received you will be contacted by a trained researcher from the CPHR to make suitable arrangements for an interview. It is possible that if we receive a lot of replies we might not be able to interview everybody, but a researcher will contact you either way to explain this. Enclosed with this letter is a participant information sheet which provides more details about the research study, and if you have any further questions about taking part please do not hesitate to contact me on the number below.

Thank you for taking the time to read this letter.

Yours sincerely,

James Caiels
Researcher
Centre for Public Health Research
University of Chester

Tel: 01244 512058

Appendix 2
Participant information sheet

Parent/Carer Information Sheet

The Paediatric Home-based Palliative Care Service

You are being invited to take part in a research study by participating in an informal interview about your experiences and views on the Paediatric Home-based Palliative Care Service. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

The aim of the study is to explore the experiences and perceptions of parents and carers who have been involved with the care of a child or young person with a life threatening or life limiting condition. In particular we wish to discuss the role that the Paediatric Home-based Palliative Care Service has played in helping to care for that individual. The focus will be on finding out parents and carers' views on their experiences of the service. The findings from the study will be used to help to decide how to develop the work of the Paediatric Home-based Palliative Care Service in the future.

Why have I been chosen?

You have been chosen because you are a parent or carer for someone with a life limiting or life threatening condition who has had some contact with the Paediatric Home-based Palliative Care Service. We are very interested to find out about your views and experiences of this.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your relationship with the Paediatric Home-based Palliative Care Service.

What will happen to me if I take part?

If you decide to take part, you should keep this information sheet, but sign and return the tear-off slip at the base, in the prepaid envelope provided, sometime during the next week. This will give your consent for a researcher from the Centre for Public Health Research at University College Chester to contact you and arrange an informal interview at a time and in a place convenient to you. At this interview, you will have the opportunity to raise and discuss your views and experiences relating to the Paediatric Home-based Palliative Care Service. The interview will last for not more than one hour and with your permission it will be audio taped and then transcribed. A written report of the study will be produced and some interview material will be used in this report. All interview material used will be anonymised and parent/carers' details will be kept confidential, so no names or identifying details will be used in the report. The audiotapes will be safely stored in a locked cabinet for the

duration of the study (approximately 1 year) and then destroyed. Transcripts of the interviews will be stored in a locked archive room for three years after completion of the study, and then destroyed. Only researchers working on the study will have access to this information.

What are the possible disadvantages and risks of taking part?

There are no disadvantages or risks foreseen in taking part in the study. However, if talking about your experiences causes you any distress you will, if you wish, be offered support from the Paediatric Home-based Palliative Care Service. You are also free to terminate the interview at any time without giving a reason or affecting your relationship with the Paediatric Home-based Palliative Care Service.

What are the possible benefits of taking part?

You may appreciate the opportunity to share and discuss your experiences and to put forward your views.

Will my taking part in this study be kept confidential?

Nobody need know if you decide to take part in this study. Taking part is strictly confidential and no names or details that could identify you would ever be used in any written or verbal report of the study.

What will happen to the results of the research study?

A written report of the study will be produced but, as already explained, nobody who takes part in the study will be identifiable.

Who is organising and funding the research?

The research is funded by the steering group of the Paediatric Home-based Palliative Care Service. Researchers from the Centre for Public Health Research at University College Chester are carrying out the study.

Who may I contact for further information?

If you would like more information about the research before you decide whether or not you would be willing to take part, please contact Catherine Perry on 01244 512029 or James Caiels on 01244 512058 or write to Catherine or James at the Centre for Public Health Research, University of Chester, Parkgate Road, Chester, CH1 4BJ.

Thank you for your interest and co-operation in this research.

✂.....

Please tear off here and return this slip in the prepaid envelope by 27/09/05.

I agree to a researcher contacting me to arrange for me to take part in an informal interview in due course.

Name:

Phone Number:

Date:

Signature: _____

Which services have you received? _____

Appendix 3
Consent form

Appendix 4
Interview schedule

Parent/Carer interview schedule

The Palliative care service

- How did you first hear about the service? (History and background of child / young person's condition).
- Can you tell me about when, and under what circumstances you were first referred to the service.
 - Why were you referred?
 - Who referred you?
 - What happened when you were first referred?
 - Did you go through a process of assessment? What did this entail?
- What did you expect to get from the service (which aspects did you access)?
 - Were these expectations met?
 - Was it different to how you thought it would be? (Different bad / good).
- Regarding the different aspects of the service accessed:
 - Is it useful / helpful / beneficial?
 - In what ways?
 - Could it be improved?
 - In what ways?
- Can you tell me of any benefits of home-based care?
 - Was home-based care 'chosen' as opposed to any other type of care (e.g. hospital)? If so, why?
- How much communication have you had with the service?
 - Was it useful / helpful / beneficial?
 - In what ways?
 - Could it be improved?
 - In what ways?

- Did the service provide you with information regarding home-care?
 - What kind of information do want / need?
 - Has this been provided?
 - Could these needs be better met? If yes, can you explain how?

- Have you used the out of hours telephone advice service?
 - Can you tell me about your experience of this?
 - Did you find it useful / helpful – in what way?
 - If it was not useful, why was this?
 - Could it be improved at all?

- Have you had any need to contact the service in an emergency?
 - Was appropriate help / support available in this event?
 - How was it provided?

Experience of being a carer

- Can you tell me about your experience of being a carer at home?
 - Could you explain any challenges that you have faced?
- Has the service been able to support you in this?
 - In what ways?
- To what extent do you feel involved by the service in being a carer?
- Are there any other ways you could be supported as a carer?

Bereavement support (if appropriate)

- Was the service able to offer support?
- In what ways was this helpful?
- Are there any other forms of support that would be helpful?
- Has there been anything that was not helpful / supportive?

Final comments

- Overall, has there been any aspect of the service that you think has been particularly valuable to you?
 - Which aspect?
 - Why?
- Overall, has there been any aspect of the service that you think could have been improved?
 - What are these?
 - How could they be improved?
- Is there anything missing from the service that should be provided?
 - What are these?
 - Why would they be helpful?
- Is there anything else you would like to say?
- Thank you for your time.

Appendix 5
Questionnaire

Questionnaire for Home Based Palliative Care Service

Please tick the most appropriate answer

1. Was the information provided by the Home Based Palliative Care Service prior to the first visit:

- **Excellent**
- **Good**
- **Satisfactory**
- **Poor**

2. On initial visit did you understand the purpose of the service and how the service could be of assistance to you and your family?

- **Understood**
- **Unsure of details**
- **Did not understand**

3. Was the information given regarding how to contact the team?

- **Excellent**
- **Good**
- **Satisfactory**
- **Poor**

4. Was the frequency of contact via telephone and home visits:

	Telephone	Home Visits
Excellent		
Good		
Satisfactory		
Poor		

Comments.....
.....
.....

5. Was the content via telephone and home visits:

	Telephone	Home Visits
Excellent		
Good		
Satisfactory		
Poor		

Comments.....
.....
.....

6. Was the support offered by the Home Base Palliative Care Team:

- **Excellent**
- **Good**
- **Satisfactory**
- **Poor**

Comments.....
.....
.....

7. Please indicate to what extent the Home Based Palliative Care Service covered all of your needs. 1(poor) to 6 (excellent)

- **1**
- **2**
- **3**
- **4**
- **5**
- **6**

Is there anything else you would like to see as part of this service?

.....
.....
.....

Appendix 6
List of comments from questionnaire

Question 4 comments

1. This service proved invaluable to myself during the time I was able to use it. It worked very well alongside the services provided by Claire House, and gave a lot of relief to myself to know this level of help was available
4. The team were always very helpful and sensitive .
11. A nurse from the team came out within a few hours of me ringing to change my child's Mickey button which the NHS nurse wasn't able to do until the next day.
12. wasn't sure exactly when it would be appropriate to use this service, contact GP or others

Question 5 comments

1. The advice given was always appreciated and helped me through several difficult times
4. The team were always very helpful and sensitive
11. Several times I have contacted the nurse for various reasons, honestly this has been a lifeline for me in emergency situations
12. On occasions I did use the service, the advice was good and call outs to home very quick

Question 6 comments

1. Whenever I had an issue of concern or query and rang the care team they always arranged a home visit
3. Very accessible service, friendly, helpful, reliable and supportive.
7. It is very responsive but I am concerned that as more families use the service more resource in experience staff are required
11. On leaving Alder Hey I was given no instructions how to deal with my child's gastrostomy - the nurses came out the next day to explain and made daily visits to assist me in cleaning and dressing my child

Final comments

4. It is a fantastic service, carried out by staff who are both informative, professional and yet relaxed
7. The service is very good but it may suffer from its success if more resources are not allocated
11. My child has had a few hospital stays and the nurse has come out to visit when we have arrived home. The reassurance they give is excellent.