

ORIGINAL ARTICLE

# Exploring perceptions of psychological services in a children's hospice in the United Kingdom

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## ABSTRACT

**Background:** The provision of emotional and psychological support for all family members who need it is an essential element of holistic palliative care. Within East Anglia's Children's Hospice, teams of professionally trained and experienced workers offer psychosocial support to all family members at all times during the child's and family's journey. However, the effectiveness and appropriateness of current psychosocial provision is unclear, as is the requirement for any additional psychological services.

**Objective:** The purpose of this study was to elicit perceptions about current psychological support within the hospice from a group of stakeholders (parents, hospice staff, and external professionals).

**Method:** Forty-five parents participated in family focus groups, telephone interviews, individual interviews in their home, or a web-based survey. Ninety-five hospice staff (including nurses, carers, play specialists, therapists, and family support practitioners) and 28 external staff (including physicians, nurses, and commissioning managers) were seen using a mixture of focus group and individual meetings. Focus groups and meetings were held at the hospice building or at an external venue. Interviews were recorded and transcribed verbatim and analyzed using thematic coding.

**Results:** Two main themes addressing perceptions of current psychological provision emerged: "understanding psychological support" and "unmet psychological need." Subthemes linked to support included choice, staff roles and labels, communication, and flexibility, whereas the themes within unmet need had a stronger focus on people and problems.

**Significance of results:** Understanding different user perspectives is an important first step in enhancing current psychological provision; operationalizing the findings will be challenging.

**KEYWORDS:** Psychological support, Children, Perceptions, Hospice, Family support

## INTRODUCTION

The vision of the Association for Children's Palliative Care (ACT) and Children's Hospices UK (CHUK) is that:

Every life-limited child or young person in the UK, regardless of race, religion, age or where they live has access to sustainable, holistic, family-centred and high quality palliative care (ACT/CHUK, 2009)

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Encompassed within this vision is the provision of psychological services as constituent elements of each stage of the ACT pathway, supporting the inclusion of psychological services for young people

and their families living with life-limiting and life-threatening conditions outlined in *Aiming High for Disabled Children* (DH, 2007) and *Better Care: Better Lives* (DH, 2008).

Psychology has made significant contributions to the study of death, dying, palliative care, and bereavement, not only from an academic perspective but also from assessment of, and interventions with, patients receiving end-of-life care and their families (Haley et al., 2003). As the emotional support of such patients and families is the shared responsibility of all involved professionals (Crawford, 2004) psychologists also have a role in facilitating the delivery of effective support by/through others.

Adult palliative care has been the focus of much of the research into the psychological impact of life-limiting/life-threatening conditions and their treatment, particularly for patients with cancer, with considerably less attention being given to children, and in particular children with complex needs arising from disability or illness, or a combination of both, where families are living with a condition over the longer term. Similarly, clinical psychological services have greater prominence in adult palliative care, as is evidenced by the British Psychological Society's (BPS) publication of a framework for psychologists working with adults receiving end-of-life care (British Psychological Society, 2008). No equivalent guidance exists for those working with children receiving end-of-life care. It is also evident that within the adult population there is inequality of access to palliative care services, with the Office for National Statistics reporting in 2005 that 95% of people in palliative care units had a diagnosis of cancer. This has implications for the caseload of professionals working within those units. Within pediatric palliative care cancer has also been the area in which most psychological research and clinical energies have been focused, with a wealth of studies documenting the psychological concomitants of this disease and its treatment for children and their families, both in the short and longer term. However, there is a broad range and complexity of childhood pathologies leading to palliative care requirements. Furthermore, as advances continue to be made in the medical and nursing management of children and young people with complex health needs, increasing numbers will live longer and the numbers and complexity of such patients accessing palliative care services will continue to grow, with repercussions for all involved professionals.

For the majority of children and young people with life-limiting/life-threatening conditions who also have complex health needs, it is parents, and particularly mothers, who are the main carers. The amount of support received from statutory and voluntary

agencies varies, but it is evident that the strain on a family resulting from looking after such children can be considerable (Brehaut et al., 2011), with elevated levels of stress, distress, and exhaustion reported (Yantzi et al., 2007; Rodriguez & King, 2009). However, it is also important to recognize that such stress is often in the context of positively valuing the child and the caring role (Stainton & Besser, 1998; Oulton & Heyman, 2009). Frequently families become isolated from their friends and extended family and this lack of support can further increase stress levels (Carnevale et al., 2006). Even when support is available, some parents will not access it because of their concerns about the risk of emotional or physical harm to their children from doing so (Oulton & Heyman, 2009). The costs of raising a child with disability (Sloper & Beresford, 2006) and the need for specialized equipment to care for such a child can result in parents feeling like prisoners in their own homes (Brinchmann, 1999) and the caregiving responsibility can extend to other family members, including siblings (Roberts & Lawton, 2001; Heaton et al., 2005). Furthermore, the children themselves can become isolated as care becomes focused on their medical and physical needs, sometimes to the detriment of their emotional, social, and spiritual needs.

With the introduction of palliative care services to a child and family there is the opportunity to alleviate some of these problems. Elements of care may be delivered in a range of settings (home, school/college, hospital, hospice) and professionals, including psychologists and others providing psychosocial support, may work at any of these locations. Evaluation of palliative care has focused primarily on assessing aspects such as the impact of short break/respite care on parental stress (Sherman, 1995), access to, and satisfaction with, services (Maynard et al., 2005; Eaton, 2008; Grinyer et al., 2010), and parental perceptions of bereavement services (Davies, 2005; Wilkinson et al., 2007; Agnew et al., 2010). What has not been well studied to date is the need for, or impact of, specific psychological interventions with children and/or families. Although the consensus is that psychological support should be an integral part of pediatric palliative care, the lack of robust outcome measures and the widespread use of nonvalidated satisfaction measures as tools for evaluating the effectiveness of interventions have hampered the development of an evidence base. Furthermore, family and staff perceptions of psychological need within the hospice framework have not been well studied.

In 2010, the Department of Health made funding available for service improvement initiatives in children's palliative care services in the United Kingdom. One of the funded projects focused on the provision of

psychological services in a children's hospice (East Anglia's Children's Hospice [EACH]), with the aim of reviewing the way supportive care is currently delivered, and for this to inform the development of a model of psychological support that assesses need in a consistent and systematic way using evidence-based techniques and tools, identifying and targeting areas of assessed need, and providing appropriate levels of intervention to meet that need (EACH, 2010). The findings concerning perceptions of existing psychological support and the need for psychological services are reported in this article.

## METHOD

All of the evaluators involved in this study were independent of the hospice and were unknown to any of the participants prior to the start of the study. All had a background in health and were experienced researchers. Three of the evaluators (JW, BL, and KC) were appointed as individual project leaders for this and two other Department of Health projects; JL was appointed as the project manager for all three projects and LA was the project assistant.

Participants who had used or provided services were recruited: families, external staff, and internal staff. The hospice cared for 464 families in 2009 (including bereaved and prebereaved), with increasing numbers of end-of-life referrals being received as a consequence of the introduction of local neonatal and oncology pathways. The hospice offers both in-house and community services covering a wide geographical area across four rural counties. Staff tend to be based in one of the three localities, with relatively few working across sites. Links with local services vary between localities, as does the provision of, and access to, community based National Health Service (NHS) services.

Families were invited to participate via the organizational newsletter, circulated to ~350 families across the region, and through fliers and posters in the hospice buildings, and at hospice-run events. All families who accessed the services of EACH were eligible for participation. Families were given a choice about whether they wished to participate in a focus group, individual interview, or online survey. Hospice staff were invited to participate via email (sent to all hospice care staff) or by direct contact with the project manager, and external staff were contacted via the local palliative care strategy/steering groups.

All participants received information about the project and were asked to complete a consent form. All were made aware that participation was voluntary, that they could withdraw at any time, and that data collected for the evaluation would be anonymized

and destroyed on completion of the project. At the start of each meeting clarification was provided about the project brief; the role and professional background of the facilitator(s); and the plan for the transcription, analysis, and dissemination of the findings. For the three focus groups involving parents, lunch was provided and parents were offered the opportunity to have their children (including siblings) looked after by hospice staff.

The interviews were undertaken by either one or two of the authors (JW, BL, and/or JL) and used a guided conversation technique. The question schedules were developed by two of the authors (JW and JL) and before use were sent to and agreed to by the chair of the Hospice Family Forum (family schedule only). Questions were developed drawing on the outcomes of previous satisfaction surveys for families, staff, and external staff and expectations from the project brief. Participant experiences and expectations of psychological services were explored and participants were asked to identify any gaps in service provision. Focus groups were held either in a quiet room at the hospice or at a venue independent of the hospice; individual interviews were held in the hospice, at the participant's home (for parents), or at the participant's place of work (for external professionals). Focus groups lasted from 1 to 2 hours and individual interviews from 45 to 90 minutes. Individual and telephone interviews were conducted at a time convenient to participants, which sometimes involved evenings. Focus groups with parents were held on the weekend to increase the likelihood of participation, whereas meetings with hospice staff and external professionals were held during the working day.

Thirty-seven parents participated in one of three family focus groups ( $n = 11$ ), telephone interviews ( $n = 11$ ), or individual interviews ( $n = 15$ ) in their home. A further eight parents completed the online survey. Ninety-five hospice staff (including nurses, carers, therapists, and family support practitioners) and 28 external staff (including physicians, social care staff, nurses, and commissioning managers) were seen using a mixture of focus group and individual meetings.

## Analysis and Reporting

All participants agreed to have their interviews recorded, with the exception of two meetings at which detailed notes were taken. Interviews were transcribed and analyzed using basic thematic coding to index and manage the data, and the main themes were further coded and clustered into subthemes. The analysis was undertaken by the first author, who read and reread the transcripts to become familiar with the data. The first and last author agreed the themes.

As the evaluation was small and related to a comparatively limited group of staff and families, illustrative quotes from participants have only been used if their source was able to remain anonymous and confidentiality was not compromised. Quotes have been identified by participant type and meeting number. Specific participant demographic data were not collected for this evaluation, other than broad categorization of participant type.

## RESULTS

In this section, quotations are juxtaposed with discussion to illustrate the themes from the perspective of the parents, hospice staff, and external professionals. Two main themes addressing perceptions of current psychological provision emerged: “understanding psychological support” and “unmet psychological need.”

### Understanding Psychological Support

#### *Choice*

Choice is one of the tenets of the EACH model and includes giving families choice with regard to the type of support they would like and where they would like it. Families appreciated this choice when they were able to exert it and also felt that having choice resulted in them not feeling pressured about which aspects of the service they used. However, when choices could not be accommodated, disappointment and feeling that their needs had not been met could result:

Sometimes I think it is difficult to access things and whether that's a communication thing or rules and regs that we as parents don't really know [Parent, 20].

Whereas many parents developed a good rapport with particular staff, some did express difficulty engaging with specific individuals and wanted more choice about whom they could see. The perception of some staff was that the families did not have a choice about whom they saw because of the rigidity of some of the roles (discussed later):

Sometimes we need to respect what the family say they want. We're letting them choose where they receive care; we should let them choose who they wish to share things with [EACH staff, 32].

Both families and staff expressed dissatisfaction with situations in which one professional, such as a nurse, had to stop supporting a family and another staff member, such as a family support practitioner, took

over (thereby removing any sense of choice), such as end-of-life moving into post-bereavement care. This has been and continues to be a source of distress for some, particularly in those situations in which individual staff have had a longstanding relationship with a family. In some cases the transfer of support was perceived to be very abrupt and the need for a more gradual transition was highlighted by both staff and families.

#### *Roles and Labels*

The EACH model of care is focused on a holistic vision, and within that framework the need for psychological care is currently addressed by a variety of professional groups. However, there is a lack of clarity about who does or should be undertaking this and what constitutes “psychological support.” Similarly, families have varying expectations and experiences of how their psychological needs are – or are not – addressed and by whom.

Within the current organizational structure of the hospice, the specialist interventions for providing psychological care are delivered by the family support teams (FST) but, as indicated by both parents and staff, nursing staff from the care teams have a crucial and valued role to play in supporting families. There is, however, some confusion surrounding the distinction between “support” and “therapy.” In some situations, families clearly wanted “support” in terms of some practical help and a “listening ear,” rather than the more therapeutic intervention that they were offered:

That is where for me personally Family Support would have been really good [help with practical issues at time of death]. I didn't want therapy [Parent, 18].

The approach to clarifying the individual professional specialities of the FST to families varies, with some choosing to operate entirely under the generic term of family support practitioner (FSP), whereas others provide more information regarding their own specialist training. This did cause some confusion for families and in some cases the perception was that it had been detrimental to the therapeutic relationship, with families expressing uncertainty about whether an individual FSP was “qualified” to offer a particular therapy, as the following quote from a parent shows:

Now I don't know that they're trained counsellors, I don't know that they're BACP accredited, I don't know what their clinical backgrounds are. [Parent, 18].

Nurses and care assistants also described some tensions around *“being allowed”* to support families. Although they may not provide psychosocial support as a formal part of their job, they do offer this informally, and this is something that families appeared to value and need, and that the staff themselves considered to be part of their caring role. Their input was focused around the fact that they were there when families needed them, offering spontaneous supportive care in contrast to the more structured sessions provided by other professionals:

\You’ve given end-of-life care in the Hospice, during the night shift Mum and Dad want to talk to you, you can’t very well tell them “you have to wait” [EACH staff, 11].

Some staff mentioned feeling disempowered by the rigidity of the existing model in defining roles:

We’ve got carers who’ve got a lot of skills in that area [psychosocial support] and they feel pushed aside, excluded from being able to do that, told “that’s not your role” [EACH staff, 32].

Similarly, other professional groups of therapists who work at EACH, but are external to both the care and FSP teams, see themselves as providing informal psychosocial support:

Everything you do you are providing psychosocial support [EACH staff, 32].

These professional groups identified the importance of being able to provide “psychosocial support” when and where it was needed, with flexibility in terms of who provided that support, but at the same time recognizing that where specialist interventions are indicated staff should be directing families to providers of those interventions. Such an approach was also endorsed by families, some of whom saw EACH professionals external to the care or FSP teams as their primary source of support.

A further issue related to staff roles was the blurring of professional boundaries as the range of staff backgrounds diversified and individual staff groups took on more work. This was mentioned in connection with staff practices:

I’m finding that the boundaries are actually getting quite close now, and that’s something that I’ve got to be quite aware of [EACH staff, 2].

As well as being an issue for staff, the merging of professional boundaries was also seen as having direct implications for children:

It’s very difficult for children, isn’t it. . . . If they’ve got an emotional need . . . well “where do I take this then, do I take it to *that* person? Do I take it to *that* person?” If they are doing similar things then I think that’s confusing [EACH staff, 2].

Clarifying the roles of professionals from different professional backgrounds and having increased insight into what individuals do within a specific professional group will become increasingly important for service users and service providers as EACH extends and develops its services.

### **Effectiveness and Appropriateness of Services**

The provision of a diverse range of services is a strength of the current EACH model, with both “support” and more specialized “therapy” being constituent elements of the EACH package of care. It was clear that some families wanted support in the form of practical help and having someone there:

Just someone saying – sit down; I’ll make you a cup of tea – to me that’s psychological [Parent, 43].

Others wanted more therapeutic input – “I guess I could say [I want] more of a therapy support” [telephone survey]. However, some families felt that they were being given a service which they did not want or did not think was appropriate for them at that time, and one staff member commented “They don’t want a professional psychosocial chat” [EACH staff, 10]. Many families do not choose to access family support services from the hospice but instead just use the respite and day care facilities, whereas for others the focus of their hospice experience is the family support element – “The thing that drew me to [the hospice] was the Family Support” [Parent, 33]. Others saw the care provided by EACH as more of a package, and accessed both the respite/day care services as well as the therapeutic elements, seeing EACH services as “an absolute lifeline” [Parent, 33].

### **Flexibility and its Impact on Care**

Psychological and supportive care was provided in a variety of locations (hospice buildings, home, hospital, school) and to a range of service users (children, siblings, parents, other extended family members, and significant others). Flexibility, both in terms of where and when the services were delivered and the way in which care was provided, was a recurrent theme throughout many sessions, with both negative and positive views being expressed. As the following quote illustrates, staff could see that flexibility may come with a price in terms of what the service can

offer, with this staff member expressing the difficulty of offering a specific piece of therapeutic work with a family when they are also required to undertake other types of activities with other families that might interfere with the therapeutic session:

I do question this notion of how flexible the service is, from a therapeutic point of view. . . . actually the benefits therapeutically are being compromised by the level of flexibility that we are meant to [work to] [EACH staff 1].

A further issue with flexibility and delivery of services concerned the geographically harder-to-reach families, (some may be 90 minutes from the nearest hospice location), where travel times for either the family or staff are at the limits of what is practical. A number of staff groups talked about the time to get to some families and external professionals also commented that for some families the hospice building was too far. For some families, distance precluded them from attending some of the groups. Different approaches to psychological support of these families need to be explored.

### Communication

Whereas some families felt well informed about what was available and knew how to access support services, others were less clear about what different therapies could offer and how to get referred for specialist interventions. A number of external professionals also expressed a lack of knowledge about what EACH offered with regard to specific therapies and services: "I might not be clear what the psychosocial support might be" [External professional, 16]. Some also commented on a lack of awareness of the professional training of the FSPs: "I don't know if they have the knowledge, skills and expertise for the parents if they are struggling" [External professional, 52].

### Unmet Need

Both families and staff identified areas of unmet need, both directly from their own perspective and also indirectly (e.g., parents identifying the need for psychological input for staff to help them support their children more adequately). Unmet need was described in terms of the people who might meet the need and the areas in which additional input was required.

#### *The Need for a Psychologist*

In accordance with National Institute for Health and Clinical Excellence (NICE) guidelines for supportive and palliative care (National Institute for Health and

Clinical Excellence, 2004), all staff working at EACH offer "psychosocial support," and are working at least at level 1, with some staff working at level 2 or 3. However, specialist mental health interventions (level 4) are not currently being provided. One of the objectives of EACH is to develop as a specialist provider of children's palliative care services, and the provision of some psychological services at level 4 would be an important contribution to achieving that aim. A different issue, however, is whether it should be a psychologist providing this service and whether it should be provided by EACH or referred to the statutory sector. How the service is structured and the specific skills that are required are also areas that need to be addressed.

Views differed as to whether there was a need for a psychologist at all, whether such a person should be employed by EACH or be externally based with contracted sessions, and the extent to which that person should work with the children and families and/or with the staff. Some external professionals felt that EACH met the psychological needs of families very well and that a psychologist would not be their priority for service development. Others, however, saw that there was a need for children and families to have better access to psychological support and that this was a gap in the service, with some external professionals clearly looking to EACH to provide psychology input.

What is needed is a trained psychologist - e.g. a child might be cognitively normal but as they go through life they have issues they need to deal with. . . .not a lot of support for them. . . .it's hard to find where they can get that help, support and understanding to work through the issues as a family or as an individual [External professional, 52].

The gap in psychology services was recognized by EACH staff and external professionals as being an issue in statutory services, not just EACH, with recognition of the difficulties of accessing psychology support through Child and Adolescent Mental Health Services and/or Children's Community Health Services. Some parents also commented that they had asked for a referral to a psychologist but had not seen anyone. Other external professionals identified that some children had access to their own team's family support service and in some cases children, particularly if they were oncology patients, had external psychology provision. Nevertheless, the value to external organizations of EACH having a psychologist in their team was also identified:

If EACH could have a fairly senior psychologist who could work with our psychologist that would be really good [External professional, 62].

EACH staff identified that as the expansions in symptom management, end-of-life care, and bereavement were happening, the psychosocial side should be expanding too:

They're full to the brim and can't offer as much as I think could be useful to some families [EACH staff, 4].

### *Skills*

Whereas it was evident that further therapeutic support would be valued, participants differed in what they thought was needed. For example, one staff member suggested, "It would be great if the Hospice employed a part-time family therapist" [EACH staff, 1] whereas another participant commented "I question how we assess that actually a family therapist is needed or whether actually a family counsellor is needed" [EACH staff, 1]. It was also recognized that the important factor was for support to be as holistic as possible.

The hospice offers holistic care and as part of that holistic care the psychological aspect needs to be an important aspect of that care. And in order for a child to have the best care that they can possibly have, the mental wellbeing not only of themselves but of their family is going to have a huge impact [EACH staff, 9].

Other specific therapies mentioned by both staff and families included cognitive behavior therapy and psychotherapy, although it was acknowledged that even if a therapist with one or more of those specific qualifications was employed and an individual would benefit from one of those approaches, EACH might not be the best or most appropriate agency to meet the needs of everyone. In particular, it was felt that some mental health needs might be better addressed by other external agencies rather than the hospice.

I'm wondering about cognitive behaviour therapy, maybe...whilst being holistic is a positive you...need to be careful not to get sidetracked into stuff that maybe another agency would be better meeting those needs. ...[EACH staff, 1].

The complexity of the different systems in which children and families receive care and the relationships between them were highlighted by staff and families. Systemic working and helping staff to think systemically were identified as key components of a psychology role. Good communication and collaborative working with other staff were perceived by staff as being vital:

If we don't pull together there is a risk that children and families may only have some aspect of their support addressed [EACH staff, 17].

### **Managing Challenging Behavior**

A number of children whom EACH looks after have challenging behavior and the need for some specialist input to manage behavioral issues was a recurrent theme throughout staff and parent sessions. Currently staff may refer to external agencies and will also work with behavior teams at school or in the community, but there was recognition of the potential benefits of having someone at EACH who could help them recognize and work with complex behavior issues.

In some situations with an older child with particularly challenging behaviour, staff could feel anxious about and untrained to deal with the behavior:

It makes you feel particularly on edge...it's like working blindfolded, you don't know what's going to happen...It affects the way you care. A behaviour management programme for some of our children would make me feel secure and I would feel that I would be giving a better level of care [EACH staff, 39].

Similarly, parents also spoke of the need for some help managing their children's behavior:

Often his behaviour is awful...and it's one of the first things that goes...Someone who could look at...the complex health needs but also you've got the behaviour side of it [Parent, 20].

Another parent talked about her child's erratic behavior when he became frustrated because he could not communicate:

There's nowhere to take that. It can be very, very stressful...it would be useful to have a behavioural specialist on board [Parent, 33].

### *Working with Children and Young People*

Although the emphasis on the value of a psychologist was primarily identified in relation to parents and staff, together with a liaison role with community-based professionals, some staff did identify the need for a psychologist to work directly with the sick child. The comment was made that children rarely talk to nursing staff about dying; however, this was recognized by staff as something that must be frightening for them. Some anxieties about whether nursing staff should be talking to children about dying were also

voiced. One member of staff described being “put on the spot” by a child:

...there was a little girl in for end-of-life who came out of her room and wanted to know what would happen to her...I wasn't expecting this, she just said “what will happen to me?”. Firing all these questions at me. That was tricky. That's out of my comfort zone [EACH staff, 11].

In the same meeting another staff member described such situations as “...very challenging because that's not our remit”.

### Working with Families

In addition to the specific area of behavior management, other areas were identified in which a psychologist would be a valuable resource for working with families, including facilitation of adaptive coping with the concept of a hospice and the ramifications of that. As one parent said, “Hospices, you think of them as a place to die and not very nice” [Parent, 43].

Coming to terms with the diagnosis of their child's condition and their prognosis, diagnosis of psychopathology in parents or other family members and the implementation of specialist psychological interventions (Level 4), issues of parenting, and psychological interventions in the management of complex grief were also identified as areas in which a psychologist could work with families. As a parent said,

Sometimes it would be useful to see someone – to know if you are handling something in the right way. I have asked for a psychological referral but there is no-one out there [Parent, telephone interview 3].

Another parent commented:

I think EACH should try to incorporate more sensitivity about living with the threat of death and how it impacts on everyone, dealing with the physical pain and difficult emotions, dealing with behaviour problems, using well-grounded psychological and developmentally appropriate techniques [Parent, on-line survey].

The need for support for siblings was also identified:

I do wonder about a primary mental health worker role...the siblings often need support... younger children have emotional needs – they might be bed-wetting, doing all sorts and things [External professional, 19].

### Working with Staff

Support for staff, by providing supervision to individuals working with particularly difficult situations, was also identified: “Wouldn't it be nice to have a psychologist who could look at a case study with us” [EACH staff, 9]. Other staff talked about a wider supportive, teaching, and supervisory role:

The [psychologist] to be there for staff...to start encouraging staff to think outside certain boxes, to facilitate group work with staff... It could be peer group supervision, it could be training... [EACH staff, 2].

Another member of staff commented:

A wish list for me would be to have someone who is very experienced psychotherapeutically as a resource to staff [EACH staff, 1].

Other professionals identified the need for a stronger therapy structure within EACH and suggested that a therapy lead was required, identified as:

Someone who is strategic... just bringing that perspective to the table. In doing so we'd be acknowledging the importance and significance of therapy [EACH staff, 32].

## DISCUSSION

A number of qualitative approaches were used to obtain the views of parents, hospice staff, and external professionals about the provision of psychological services. The findings about current and future provision, together with information about how need is assessed and interventions are evaluated, formed the basis of a series of recommendations for the development of a model of psychological support.

Two main themes addressing perceptions of psychological need were identified: understanding psychological support and unmet need. The concept of psychological support was understood in a number of different ways, with staff and families having differing views as to what constituted psychological support, who should and does provide it, and the way in which it should be provided. As has been reported by others (Steele et al., 2005), the hospice was seen as a lifeline for parents, providing them with highly valued support and respite from caring. However, several elements of the current model of service delivery that were introduced to improve the care offered to children and families conversely elicited negative responses from families and staff. For example, the flexibility in terms of how, where,



and when support is provided can compromise the benefits of care and therapy when staff are unable to be as flexible as the service and families expect them to be. Similarly, the notion of choice can cause tensions about what families want and what the hospice is able to deliver with its available resources, and this can extend to the provision of psychological support. Frictions were also evident in relation to differing perceptions and expectations of who was, and should be, providing what kind of support, blurring of role boundaries, and what type of service EACH should be aiming for. Others have also identified difficulties regarding role definitions among members of the multidisciplinary team and the potentially deleterious effect this can have on the effective and efficient functioning of the whole care team (Junger et al., 2007; O'Connor & Fisher, 2011).

Similarly, a number of different unmet needs were identified, in terms of specific areas in which psychological input would be beneficial, such as managing challenging behavior, supporting staff to work with families to ensure consistency of approach and personnel, and the broader need for psychological support for staff. What was evident throughout, however, was that the holistic care of the child and family was regarded by families and staff alike as a key component of hospice provision, as has been identified previously (Kirk & Pritchard, 2011). Although there are gaps in current service provision there is, importantly, a motivation and desire to address this. The challenge now is to ensure that there is a unified understanding of what psychological support is and how it should be delivered, so that expectations are realistic and the needs of families and staff are met.

## LIMITATIONS

Because of the short time frame set by the Department of Health for completion of the project (6 months) and the need to capture the views of a diverse range of participants, it was not possible to interview participants more than once, or for participants to be involved in reviewing the findings (although the final report has subsequently been made available to all participants). One aim of the project was to engage with a diverse range of participants, including harder-to-reach families and professionals with limited time availability, so we adopted a mixed-methods approach utilizing approaches that were individual or group, face-to-face or telephone, and involved contact at home, at work, or at an external venue, as well as using an anonymous web-based survey, to facilitate the inclusion of as many participants as possible within the time frame of the project. The importance of involving key stakeholders and obtaining multiple perspectives when evaluating services has been re-

cognized (Hiatt et al., 2007), but a further limitation is the absence of accounts from children and young people who use the hospice, primarily because most do not have verbal communication skills. Although research has been conducted previously with children with communication issues (Beresford et al., 2004; Mitchell & Sloper, 2011), we had insufficient time to engage, obtain consent from, and work with a group of young people with learning disabilities in a manner that would have ensured that their voice was properly heard and documented. A number of siblings attended the family focus groups and their use of services and what they liked/would like to change was explored (via an art medium) but this did not specifically address psychological need, and is not reported here. The need for a greater emphasis to be placed on obtaining the views and experiences of children using hospices and their siblings has been identified previously, and should be addressed as services are developed and implemented (Davies et al., 2005; Malcolm et al., 2008).

## CONCLUSION

For psychological services to fulfil their potential in the delivery of care to children with life-limiting conditions and their families, including end-of-life care, there are a number of challenges that need to be addressed. These are related to articulating the role of psychological support as part of a multidisciplinary approach to care, training, and supervision needs of individuals filling the role, to ensure appropriate service provision and to acknowledge competence, and to obtain a realistic understanding by all stakeholders of what is achievable and reasonable, especially across an organization that covers such a wide geographical region. It is evident that the role of psychologist would be challenging, but as one participant commented: "It's a complicated job. Doing support with staff and parents. Maybe this is the Messiah, I don't know."

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