A review of the literature relating to the experiences of parents of children receiving palliative care in Ireland.

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Abstract

The necessity for Paediatric Palliative Care (PPC) advancement in Ireland is critical with 1,400 Irish children suffering from a life limiting condition and 490 childhood deaths annually (DoHC 2010, p.vii). 350 or 70% of these childhood deaths are due to a life limiting condition (Hill and Coyne 2012; Laura Lynn and Irish Hospice Foundation (IHF) 2013, p.2). These statistics emphasise the need for adequate palliative care services for children and their families in Ireland. Currently the lack of specialised personnel in PPC warrants action to cultivate the seeds that have been set in this specialist area (DoHC 2005; Davies et al 2008; DoHC 2010; O’Brien and Duffy 2010).

This paper presents a review and consideration of literature relating to PPC for children living in Ireland with a life limiting illness. The review was a chapter in a Final Year Proposal title ‘The experiences of parents of children receiving palliative care in Ireland’. In reviewing the literature several themes emerged however in meeting the constraints of academic writing four themes were addressed namely: the significant difference between adult and paediatric palliative care services; current service provision for families of life limited children in Ireland; education for health care professionals in paediatric palliative care; the social impact of caring for a child with a life limiting illness on a family.

Findings from the review highlight the similarities and differences between adult and paediatric palliative care services’ (Downing et al 2012; Downing and Ling 2012), the need for continuing education for professionals in this area (O’Shea and Bennett Kanarek 2013), the significant strain and joy experienced by parents and families caring for a life limited child and finally the impact on the child of living with a life limiting diagnosis (Zelcer et al 2010; Pearson 2010; Ling 2012).

Background

Palliative care in Ireland emerged in the 19th century with the opening of Our Lady’s Hospice in Dublin (Department of Health and Children (DoHC 2001). The speciality began to gain momentum in 1986 with the establishment of Irish Hospice Foundation, supporting the development of hospice and home care
services (Irish Hospice Foundation 2013). Palliative medicine in Ireland was recognised as a speciality in 1995 (DoHC 2001).

The development of PPC, has been significantly slower and the situation was highlighted in 2001 when the DoHC highlighted the need for policy development in this specialist area. Subsequent to this ‘The Report of the National Advisory Committee on Palliative Care' was published with attention given to the needs of children with a life limiting illness (DoHC 2001). This report was viewed as the blueprint for PPC mapping the future of this speciality in Ireland and it has been implemented as a national policy. Recommendations from this report indicated palliative care should be introduced at the time of diagnosis for a child with a life limiting illness with all three levels of palliative care available to the child and his/her family. Subsequent to this report the DoHC (2005) published ‘A Palliative Care needs assessment for children’, cementing the foundations for PPC and identifying a path for future developments. The most recent publication from the DoHC entitled ‘Palliative Care for Children with life limiting conditions in Ireland – A National Policy’ (DoHC 2010) evaluated current services available and made recommendations for future provision of same.

Laura Lynn Ireland Children’s Hospice, the first and only paediatric hospice in Ireland opened in Dublin in 2011 with the first paediatric palliative consultant appointed soon after (Laura Lynn 2013). The first multidisciplinary PPC conference took place from the 29th-30th of November 2013, with the aim of collaborating home, hospital and hospice services for children with a life limiting illness in Ireland (Irish Children’s Palliative Care Conference 2013).

**Introduction to literature review**

A literature review comprises of an unbiased thorough synopsis of the relevant research literature available relating to the topic being studied (Cronin et al 2008). Conducting a literature review offers the researcher the opportunity of identifying research crevices, analysing methods of previous research carried out and establishing the standard of knowledge currently known regarding the topic (Jaidka et al 2013). Completion of this process enables the researcher to recognise and evaluate what is known about a topic whilst highlighting the unknown.
This aim of this review is to consider the literature relating to parents/guardians experiences of palliative care services for a child with a life limiting illness. The findings from the review will inform the student and provide a foundation for further study of evidence to inform practice.

Electronic search engines using University of Limerick online databases included Medline, Web of Science and Science Direct, limiting years to 2009-2013 and linked with manual searches of texts available in the library. Keywords/phrases included: Palliative care, hospice care, Irish Paediatric Palliative Care (PPC), children with life limiting conditions, respite care for children with a life limiting illness and acquiring PPC services in Ireland.

Themes to emerge included, the significant difference between adult and paediatric palliative care services, the services available to families in Ireland at present, the education for health care professionals in paediatric palliative care and the social impact of caring for a child with a life limiting illness on a family. These themes will next be discussed.

**Theme One: The Differences and Similarities between Adult and Paediatric Palliative Care**

Paediatric palliative care in Ireland stands as a separate speciality albeit closely affiliated with adult palliative care (Downing et al 2012; Downing and Ling 2012. Ling (2012) argues that, salient differences exist between both fields noting that childhood life limiting illnesses are often much rarer conditions than those of adults. This supports the view of Malcom et al (2011) who articulated that many childhood illnesses require individual care and treatment due to the scarcity of the conditions encountered. Such rare conditions require specialist expertise rendering palliative care guidelines unsuitable for children (International Children’s Palliative Care Network 2013). In addition children and adults can suffer the same condition but they may take different courses of action due to different anatomy and physiology requiring individually tailored treatment and care (Get Palliative Care 2012).

Mellor et al (2011) highlighted that individually tailored treatment for children is a necessity as it is common for children with a life limiting illness to “rehearse
death” numerous times prior to the time they die requiring specific specialist care. Rarity of emerging conditions and the differing disease trajectories cause difficulty in determining a diagnosis thus proving challenging in establishing the child’s length of survival requiring the involvement of a myriad of services in the child’s life (Thompson et al 2009; Shaw et al 2010; O’Shea and Bennett Kanerak 2013). O’Shea and Bennett Kanerak (2013) revealed a significant difference here with the length of survival, as adult palliative care often warrants very short term care whereas childhood palliative care can continue for several years.

Menezes (2010) argued that with every year that passes parents become less anxious, with one mother declaring as time went by she ‘worried less and less as her child was still with her and is now at the age of 14’. PPC tends to be introduced upon diagnosis of a life limiting condition aiding parents in dealing with what lies ahead while also bettering the child’s quality of life from an early stage in the disease trajectory (Mellor et al 2011; Ling 2012). Early intervention from the PPC team allows parents to acquaint themselves with the reality of the constrictive nature their child’s life now holds and the ramifications this will reflect on their own lives while also providing them with emotional support (Klick and Hauer 2010; Pelant et al 2012).

In contrast palliative care in adults encompasses a shorter timescale as it is frequently not implemented until the final stages of life (Ling 2012; Pelant et al 2012). O’Shea and Bennett Kanerak (2013) affirm this difference indicating adults attend hospices within the last six months of life, which is incompatible with the paediatric populace due to the uncertainty of life remaining. Ling (2012) further noted that the quantity of children dying in comparison to adults is minute while Gilmer et al (2013) correlated the increased legacy of children with a life limiting illness with improved technology and medical advances resulting in diminutive deaths in early childhood. Regarding treatment and care there are numerous decisions to make such as: what treatment to choose; when and if to change that chosen treatment; or to withhold treatment altogether.

Controversially, Huang et al (2010) suggested PPC involved the use of curative care and palliative care synchronously while only palliative care is employed with the adult genre. However, Mellor et al (2011) described the approach to using
both curative and palliative treatment together as “parallel planning” emphasizing that by implementing this method of care it allows parents to maintain hope while considering the attributes of end of life care. Pelant et al (2012) continued with the argument that paediatric pain management is handled differently than adults as young children cannot communicate their pain, unable to use the 1-10 pain scale used in adults requiring other tools such as the “CRIES” (assesses crying, oxygen requirement, increased vital signs, facial expression, sleep) or “FLACC” (face, legs, activity, crying, consolability) assessment tools, an additional reason for the necessity of specialist PPC personnel. Rork et al (2013) further suggested pain management is the supporting pillar of PPC.

Children are continuously developing physically, mentally and cognitively thus requiring play therapy and education to be an imperative element of their palliative care (Ling 2012), a feature absent from adult services. The International Children’s Palliative Care Network (ICPCN) (2008) previously stated provision of play therapy and education to children with a life limiting illness is a legal right.

ICPCN (2008) acknowledged that although PPC is distinctly different from adult palliative care it inhabits certain facets including improving quality of life, reducing suffering by mitigating distressing symptoms, respecting cultural beliefs and working together to achieve a dignified death. Given the ample involvement of the family in the child’s care Foster et al (2010) observe a subsequent anomaly between both domains indicating PPC embraces care of the child and their family as a unit, while adults are cared for as independent individuals. In terms of advocacy, children are a vulnerable genre in society, requiring advocates to protect their wellbeing in making the best decisions regarding treatment and quality of life (Wright et al 2009; Stayer 2012). Stayer (2012) considers that children require advocates to assist them in their palliative care journey to achieve the best quality of life attainable while other researchers including Huang et al (2010) purport that adults make decisions independently with no requirement for advocates.

It is interesting to note that despite evident variations between both realms the majority of children are still cared for under adult services in Ireland and PPC is
under-served as a speciality (O’Brien et al 2009). From the differences stated it emerges that there are specific care requirements for children with life limiting conditions which are not widely available or evenly spread throughout the country of Ireland (O’Brien and Duffy 2010).

**Theme Two: Current Irish Paediatric Palliative Care Service Provision**

In Ireland the support of a child with a life limiting illness in the community is largely the remit of the Health Service Executive including General Practitioners, Public Health Nurses, Community Nurses, Palliative Care teams and hospice services (DoHC 2010), with additional support for life limited children coming from local voluntary organisations such as ‘Jack & Jill’ (Appendix 1)

The DoHC (2010) outlined that there are 22 paediatric units attached to various hospitals around Ireland and three tertiary hospitals in Dublin caring for children with life limiting conditions. The only paediatric palliative care team to date operate in Our Lady’s Children’s Hospital in Crumlin, Dublin (DoHC 2010) and there are only two paediatric palliative care outreach nurses one based in Templestreet hospital Dublin and the other in Our Lady of Lourdes in Drogheda (O’Brien and Duffy 2010; Early Childhood Ireland 2013). Therefore, palliative care has availability in every county in Ireland, however, specialised palliative care such as PPC units are limited with varied access dependent on geographical location (Hill and Coyne 2012). Downing et al (2012) suggested that the PPC service is found to be lacking and as such is frequently unobtainable to those requiring such services.

O’Brien and Duffy (2010) evaluated the role of the children’s nurse in the Irish community palliative care findings from this study indicated that the limitation of PPC services puts pressure on families to travel to Dublin in order to receive adequate care for their child. This causes distress and upheaval of family life where they are almost forced to create a new life in Dublin leaving families crippled with exhaustion (O’Brien and Duffy 2010). More recently, in Ireland Nicholl (2012) in a qualitative phenomenological approach, interviewed mothers (n=?) indicated this situation remains a concern describing the heightened stress journeys cause in discussing the home as “the outside world”, hospital as “the inner world” and travelling between the two as “the going between worlds”.

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Nicholl (2012) continued in stating mothers are required to cater to their child’s needs while also ensuring safety with travelling to “the outside world”. In obtaining services in Dublin the families were faced with troubles in sourcing accommodation as family support was absent in these terms (DoHC 2010). Downing et al (2012) suggested PPC envelopes a basic human right and the drought of services available to so many children is unfair noting that General Practitioners are still providing care to children with a life limiting illness in both general hospitals and several adult hospices. This system was considered by DoHC two years ago in 2010, as unfavourable to these seriously ill children given the fact staff are not competently trained and educated to cater to their every need. The DoHC (2010) recommended the need to commission suitably educated professionals to redress this situation.

However, since then efforts have been made to improve this inadequacy with the development of projects such as the Ronald McDonald House Crumlin offering families support in their emotional journey, providing a home away from home (Ronald McDonald House Charities 2013).

There is a plethora of literature suggesting families’ principal desire is to care for their child at home allowing the location of their child’s death to be in the home (DoHC 2005; DoHC 2010; O’Brien and Duffy 2010; Neilson et al 2010; Zelcer et al 2010; Crozier and Hancock 2012). The Irish Association for Palliative Care (2012) communicated that parents find solace in being involved in the care of their child, in being the primary caregiver which is to the fore in the home. However, in most previous incidences, home care is not achievable due to the scarcity of resources and services available. Although community services are improving direct specialist care will not be within reach for many years to come, drawing attention to the need to address this weakness (O’Brien and Duffy 2010).

The DoHC (2010) suggested respite services for children with a life limiting illness are in short supply with certain paediatric units of hospitals offering this service to families. Respite care is an essential component of PPC offering both parties a break (Laura Lynn and IHF 2013). The introduction of the Laura Lynn Children’s Hospice in 2012 has responded to a need for families around Ireland.
The first of its kind in Ireland, children are finally being recognised in this sense (Laura Lynn 2013). Steps towards improved care are visible with the first paediatric palliative consultant in operation since the opening of the Laura Lynn Sunshine Home, indicating action is progressing in addressing the weaknesses in introducing direct services and educating staff for these children. The child endures the physical pain of the illness but the surrounding family bear the brunt of the emotional pain and sorrow upon watching their loved one languish in anguish and suffering as they deteriorate.

The Jack and Jill Children’s foundation (2012) also supports the families of children with a life limiting illness, offering a life line in assisting the possibility of caring for their child at home. The foundation raises €3.6 million annually to offer relief to these families aiding them in accessing specialist care, home respite care and essential equipment required for the care of the child at home.

**Theme Three: Education for Health Care Professionals in Paediatric Palliative Care**

This theme focuses on education currently available for nurses in the area of PPC.

**1.0.1.1 Nurse Education in Paediatric Palliative Care**

The Irish health care system currently involves nurses offering PPC to children when they have no specific qualification in this speciality (O’Brien and Duffy 2010). In 2010 Ireland offered no undergraduate or postgraduate courses to the public in the PPC speciality (O’Brien and Duffy 2010). In 2014 this situation is unchanged in terms of undergraduate courses, though some small developments have been seen upon recommendations from DoHC (2010) with Hill and Coyne (2012) indicating PPC has been integrated into existing postgraduate courses. Many colleges including Trinity College Dublin (TCD) (2013) and NUI Galway (2013) offer a postgraduate masters/postgraduate diploma in palliative care with PPC integrated into the curriculum. TCD is the only college in Ireland to offer a post registration course specific to PPC entitled ‘Children’s Palliative Care’ where successful candidates receive a minor award (An Bord Altranais 2012; TCD 2013). The Irish Association for Palliative Care has also established a PPC course entitled ‘Caring for a child with a life limiting condition – Level A programme’,
allowing registered general nurses to gain specific paediatric palliative care which has been operating since 2011 (Health Service Executive 2013).

O’Shea and Bennett Kanarek (2013) argued that a possible reason for the deferral of PPC is the deficiency of education available for health care professionals holding the system back from aspiring to meet standards of other specialities. O’Shea and Bennett Kanarek (2013) continue in emphasizing that the future development of PPC is dependent upon educating nursing staff to meet the needs of these children.

Morgan (2009) also indicated that delayed action for within the PPC speciality may be due to the lack of awareness or even ignorance to accept the fact that children do die. Recently however, distinct attempts to increase public awareness of children suffering with a life limiting illness are visible with ‘National Pyjama Day’ implemented annually since 2011 nationwide (Early Childhood Ireland 2013). As a direct result of this campaign funds raised have allowed for five more PPC outreach nurses to be appointed in communities across Ireland, supporting families in the home (Early Childhood Ireland 2013). A new initiative to create awareness for children with cancer was rolled out in 2013, with the ‘Light It Up Gold’ worldwide campaign which was carried out throughout the month of September seeing many buildings in Ireland shining bright in gold to support these children (Light It Up Gold 2013). Such increased awareness and the development of sustainable finding for support must inevitably auger well for improving the quality of life that is left for both the child and family.

**Theme Four: The Social Impact of Caring for a Child with a Life Limiting Illness**

There is wealth of literature detailing the effects that caring for a child with a life limiting illness has on parents. (Zelcer et al 2010; Knapp et al 2010; Klick and Hauer 2010; Pearson 2010; Ling 2012). Zelcer et al (2010) suggests that financial and social stresses are to be anticipated with home care, advising parents that maintaining normality is a key coping mechanism. This is in keeping with Ling (2012) who argued that considering the majority of care provided to the child occurs in the home, challenges arise in juggling care with everyday family life. Parents are confronted with obstacles to overcome including financial, emotional,
physical and psychological indicating that parents feel trapped in their own homes with a loss of normalcy to everyday life. The Cliona Ring Foundation was established in 2007 to offer financial support to families with children who suffer with a life limiting illness. This organization is credited in attempting to combat the strain of financial hardships for families. Croke Park Stadium, Dublin held a fundraising event on the 19th of December 2013, where the public were invited to attend and sing Christmas carols in aid of the Cliona foundation (Cliona’s Foundation 2013). This theme is described under the following subheading, parental struggles, impact on siblings and the impact of a life limiting illness on the child.

Parental Struggles

Parent struggles were identified in a previous qualitative study by Zelcer et al in London in 2010 where semi-structured focus group interviews were used to determine parent’s (n=25) struggles of caring for a child with a life limiting condition. From the findings, parents described how discussing their child’s imminent death with them was a major struggle. Parents believed home care was the better option for the quality of life of their child and family. Although this study has limitations with a small sample size of parents generated from one location, the findings have significant inferences for care.

Parents often feel compelled into reducing work hours to care for their dying child putting further pressure on the financial burden (Knapp et al 2010). While respite services may assist parents in this situation offering time for recovering, relaxation and space to breathe, parents frequently rejected such services through feelings of guilt in abandoning their child or feeling a sense of anxiety due to fear of being absent for their child’s death (Ling 2012).

Corkin et al (2007) noted that as some life limiting conditions can be genetic there is an increased risk of conceiving a second child with this condition, highlighting the major strain this imposes on a marriage. An American qualitative study by Knapp et al (2010) highlighted this point in their findings from surveys carried out, observing that 71% of (n=85) parents made sacrifices to care for their child, while 44% (n=37) encompassed little desire for social interaction and a further 48% (n=37) considered the thoughts of more children undesirable due to the
hardship they endured to date. These findings suggest that parents are vulnerable to feelings of blame, unfairness and anger when caring for a child with a life limiting illness adding fuel to the fire of marital stress (Klick and Hauer 2010). Literature suggests parents feel they have failed in their duty to protect their child upon diagnosis of a life limiting illness (Dunlop 2008; Pearson 2010). Moments of realization that nothing can be done for their child consequently leave them feeling helpless wishing they could take the place of their child (Menzes 2010). From the literature it is clear that not only parents but all members of the family are affected by the devastation of a child suffering with a life limiting illness.

**Impact on Siblings**

Siblings ultimately suffer the consequences of the extensive workload involved in the care of their brother or sister. Little attention remains for them once the ill child has been cared for leaving siblings feeling like outsiders, isolated from their family (Klick and Hauer 2010; Puckey and Bush 2011). O’Brien et al (2009) agreed with this point previously, suggesting in their Irish study of sibling (n=25) coping abilities that siblings are at high risk of being consumed by isolation with the majority resenting their brother/sister which manifests into behavioural problems. Furthermore, Brown (2009) suggests that a sibling’s coping ability is dependent on their age, gender and hierarchy in the family (Brown 2009; O’Brien and Duffy 2010) and that attention seeking behaviour was normal for siblings, in portraying their anger for the disruption their brother/sister was causing to their life. A subsequent English qualitative study by Welch et al (2012) found from their surveys that 93% (n=71) of well siblings would only receive attention from their parents in the absence of their ill sibling. This is similar to the findings of Brown (2009) who also described that the deficiency of attention affects the well child mentally causing them to feel lonely and an unimportant member of the family unit.

Research also indicates that children who are excluded from the care of the dying child endure trauma and relationship issues with their family as a result (Ewing 2009), with Brown (2009) suggesting inclusion in care proves an important factor in the siblings’ coping ability. In a more recent study, O’Brien and Duffy (2010) suggested that avoiding isolation was vital for the sibling’s wellbeing and
isolation has been reported to be reduced when the dying child is nursed at home. The home environment allows for less disruption to family life offering opportunity for close bonds to be formed (O’Brien and Duffy 2010). This is in keeping with earlier findings of Siden et al (2008) who purported that spending time together in the final stages of life helps siblings to cope better with grief related symptoms following death. In terms of respite and benefits to siblings, Welch et al (2012) conducted an English study surrounding the query as to whether respite care of the ill child benefits other siblings. This qualitative study revealed from surveys carried out that 81% (n=65) of siblings felt protective of their ill brother/sister and felt guilty enjoying activities their sibling could not partake in due to their illness therefore tended to participate only in the absence of their ill sibling (Welch et al 2012). The study further disclosed that growing up in this environment can emanate positive aspects for siblings with 87% (n=72) of the children developing a sense of heightened love, acceptance and increased empathy for their ill sibling, helping them to develop a caring and sensitive personality (Welch et al 2012).

In light of the identified support needs for siblings, AnamCara an Irish organisation, was established to support siblings and parents through the bereavement process aiding them in continuing their path in life (AnamCara 2011). This relatively new support is the subject of ongoing audit and evaluation.

1.0.1.2 The impact of a life limiting illness on the child.

A dearth of literature presently exists regarding the impact a life limiting illness places on the child patient (Durualp and Altay 2012). Receiving the diagnosis of a life limiting illness is a highly traumatic experience for a child affecting them physically, emotionally, socially and psychologically (Durualp and Altay 2012). In Ireland DoHC (2010) voiced concern at the lack of normalisation in the life of a child with a life limiting illness.

In 2008 Dunlop noted that children are aware of their impending death. In most cases, even though they may not speak directly about it, they will introduce it into conversations in other ways. Wilson et al (2011) an American study using a case study design, described the experiences of children (n=3) and the suffering they endured with a life limiting illness supported this statement stating a child
disclosed they would watch over their family from heaven, as well as selecting toys to take with them, indicating they are aware of their death. Wilson et al (2011) further revealed how children are forced to grow up prematurely, unable to play with friends or toys due to their condition. The study further disclosed that children expressed sadness because of inability to attend school affecting their social life and restricting time with friends.

Dunlop (2008) noted that parents often refuse to impart information about death to their children as they wish them to maintain hope and eliminate anxiety. Not discussing issues regarding death with their child avoids helping the child to confront their fears, in turn hampering efforts made to improve their quality of life (Dunlop 2008). Wilson et al (2011) recognised a child’s dependence on their parents when they interviewed a child asking what action helps to reduce pain with the child answered “the presence of their parents”.

Several Irish organisations cater for children with a life limiting illness in fulfilling their dreams such as Bubblegum Club (2011), Make a Wish Foundation (2013) and Share a Dream Foundation (2013). Share a dream foundation (2013) hosted the ‘Children of Courage Awards’ in Clontarf Castle in Dublin on the 30th of November 2013, acknowledging the bravery of children fighting a life limiting illness. Fulfilling a dream allows the child to enjoy life fully, if only for a short period obliterating thoughts of pain and sorrow (Ewing 2009). In the latter years, Downing et al (2012) argued that PPC envelopes a basic human right and the deficiency of services available to so many children is unfair. Children are the future of tomorrow, children with a life limiting illness have this opportunity seized, quenching their flame prematurely, placing devastation on the doorstep of all those who survive such a tragedy.

**Conclusion**

This literature review is limited by the constraints of academic writing. Thirty six studies were reviewed, with the majority being of a qualitative design from countries including Ireland, United Kingdom, America and Australia.

In theme one the substantial difference between PPC and adult palliative care was noted with emphasis on the varied cognitive abilities and maturity of a child
requiring individually tailored care while also ensuring to encompass the family and child as a unit in care (Downing et al 2012; ISPCN 2013).

Theme two considered service provision for PPC in Ireland and suggests a slow but positive development in recent years (O’Brien and Duffy 2010) with the implementation of the Laura Lynn Children’s Hospice and the appointment of specialist PPC personnel (Laura Lynn 2013).

In theme three there is a paucity in third level educational opportunities for nurses with only one college in Ireland offering a specific postgraduate PPC course and currently no undergraduate PPC programmes (O’Brien and Duffy 2010; Hill and Coyne 2012). However the Level One programme for professionals caring or children with a Life Limiting illness offers valuable opportunity for the development of knowledge and skills in this area.

The final theme, highlighted that families can struggle under the challenges involved in caring for a child with a life limiting illness while also attempting to salvage some normalcy in their own lives (Ling 2012).

The literature suggests PPC is significantly different to general palliative care while encompassing certain similarities (Ling 2012). Developments within the Irish health care system indicated this difference was not previously recognised but has come to light in previous years with the implementation of PPC as a separate speciality (Downing et al 2012). The distance PPC has come since implementation deserves commendation although many developments are still clearly required. From this brief literature review it emerges that PPC services in Ireland are under continuous pressure to provide a quality service to children and families. With the support of voluntary organisations, and health service providers, families and professionals work together to make the world of a child with a life limiting illness a place of comfort and hope.
References


Irish Association for Palliative Care (2012) ‘What are the factors that allow parent caregivers to survive and even grow in the face of the stressful circumstances of caring for a child with a life-limiting illness?’, [online], available: http://www.iapc.ie/pdf/1357569571_609.pdf [accessed 07 Jul 2013].

Irish Children’s Palliative Care Conference (2013) Children's Palliative Care: Connecting home, hospital and hospice – A Multidisciplinary Conference’,


Appendices

Appendix 1


The Jack and Jill Foundation

“The Jack & Jill Foundation provide home respite to families with children up to the age of 4, with severe neurological developmental delay and non-oncology palliative conditions requiring extensive medical and nursing care at home”.

Services include:

- Home visits by a Liaison Officer/Nurse. The nursing team is available Monday-Friday and covers all of Southern Ireland.

- Advice on caring for a child at home.

- Advice and information for families on how to access all the services their child may require.

- Listening to what families want for their child, and making representations on their behalf.

- Direct funding available for families to enable them to purchase home respite care.

- Lobbying Government/Health Boards/HSE on the families’ behalf.

- Bereavement support and follow up.