

# Disclosing terminal diagnosis to children and their families: palliative professionals' communication barriers

Coad, J. , Patel, R. and Murray, S.

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5 **Disclosing Terminal Diagnosis to Children and their Families: Palliative Professionals'**  
6 **Communication Barriers**  
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8 Abstract:  
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11 Few studies have fully explored the problem of communication barriers in paediatric  
12 palliative care, particularly the detrimental effects of poor interaction between staff and  
13 families on children's health and well-being. A literature review was undertaken to expand  
14 the current body of knowledge about staff to patient communications. Articles meeting the  
15 inclusion criteria ( $N = 15$ ) were systematically read and summarised using a data extraction  
16 sheet. A narrative synthesis identified five overarching themes as barriers to communication.  
17 Improvements in staff education and individualised palliative care plans for children and their  
18 families may help to overcome communication barriers.  
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33 Keywords: Communication Barriers, Diagnosis, Palliative Care, Children, Young People,  
34 Staff Competence  
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## Disclosing Terminal Diagnosis to Children and their Families: Palliative Professionals' Communication Barriers

It is fundamental that children with life-threatening illnesses and their families have access to health care providers with excellent communication skills. Such communication is crucial as it forms the gateway to receiving and understanding information about the child's diagnosis and decline. In addition, communications allow patients and their families the opportunity to make choices about the time remaining to them. Despite the fundamental importance of effective communications during initial diagnostic disclosure, it is precisely during this time that communication barriers between patients and providers can present themselves. These barriers can negatively impact the quality of palliative care for children and their families.

In June 2010, the Department of Health in the UK released a call to apply for funding to support projects focused on benefitting the lives of children and young people with palliative and complex care needs. Researchers at Coventry University, UK, were successful in gaining over £1.3 million for a program of work that included an evaluation of 55 children's palliative and complex care projects. This evaluation framed the current review. Past literature indicates that palliative care staff caring for children and their families lack knowledge about effective communications during diagnostic disclosure (Back et al., 2007; Sheetz et al., 2008), confidence in communicating sensitively with children and families (Hanett et al., 2009), and formal training and guidelines for effective communication for the children's palliative care staff (Davies et al., 2008; Ferguson, 2007).

During the initial diagnostic disclosure, staff members must explain highly sensitive information to families. This information might include results of tests and treatment options. In one study, palliative care staff and families reported that the most important milestones

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3 during diagnosis were symptoms, what tests to expect, and the actual diagnosis (Wood et al.,  
4 2010). Conveying such critical information presents a challenge for health care providers,  
5 possibly because the task calls for communication skills that go beyond basic clinical training  
6 and combine complex medical issues with patient centred care (Back et al., 2007). Children  
7 and families perceive inadequacies in the communication skills of palliative care staff (Catt et  
8 al., 2005; Davies et al., 2008; Ferguson, 2007). This inadequacy in communication is an  
9 increasingly significant problem as the annual number of children likely to require access to  
10 palliative care services in the UK, excluding neonates, is estimated to be 20,100 (Palliative  
11 Care Statistics for Children and Young Adults, Department of Health, 2007).  
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24 Improved communications between health care providers, children and their families  
25 are one of the most important factors in enhancing quality of care in the paediatric setting  
26 (Catt et al., 2005; Contro et al., 2004; Ferguson, 2007; Kerzman & Smith, 2004; Mack &  
27 Wolfe, 2006). Additionally, the difficulties experienced in communicating with children and  
28 young people are the primary reason qualified nurses felt poorly prepared to work in  
29 paediatric health care (Kerzman & Smith, 2004). The current review explores these issues  
30 specifically focused on diagnostic disclosure.  
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40 The available literature either focuses on staff communications with children and  
41 families (a) within a broad healthcare setting, (b) within palliative care, or (c) during  
42 diagnosis or critical interactions. No known literature simultaneously addresses these issues  
43 Thus, present aims are to identify the primary communication barriers that paediatric  
44 palliative care staff and service users report during initial diagnostic disclosure. Also, we  
45 explore whether there are specific communication skills needed to disclose diagnosis to  
46 children with life-threatening illnesses and their families.  
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6 Method

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9 For this review the term 'communication barrier' refers to the perceived factors  
10 interfering in the meaningful interpretation of the information needed to enable patients and  
11 providers to obtain, process, and understand the basic health information and services needed  
12 to make appropriate health decisions. The term 'children and young people' refers to  
13 individuals under the age of 18 years. Considerable variation was noted in the literature  
14 regarding the preferred title used to refer to a senior healthcare professional. The terms  
15 'paediatrician', 'physician', 'consultant' and 'doctor' refer to senior healthcare professionals  
16 involved with the provision of palliative, end of life and complex care for children and young  
17 people.  
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20 A systematic search was conducted using search terms that included Communicat\*,  
21 Barrier, Difficult\*,Problem\*, Diagnosis, Prognosis, Paediatric, Pediatric, Palliative care, End  
22 of life, End-of-life, Complex care, Child\* Adolescen\*,Young person, Young people,  
23 Famil\*. Databases were searched from 1996 – 2011 and included Academic Search  
24 Complete, ASSIA, CINAHL, Google Scholar, Medline, PsychInfo and Scopus. The reference  
25 lists from retrieved papers were also checked to identify any other relevant studies. The  
26 inclusion criteria stipulated that studies needed to be published in English and had to address  
27 one or both stated aims. Studies that examined communication barriers between  
28 professionals, children and families in end of life care or complex care were included if  
29 findings were easily transferable to the children's palliative care setting.  
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32 A total of 15 articles met criteria and are marked with an asterix in the references.  
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34 They focused either on communication barriers of professionals, children and families in  
35 palliative care services (11) or during diagnostic disclosure in palliative care services (4  
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3 articles). Limitations of the review resulted from the poor availability of relevant articles that  
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5 were up to date.  
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## 8 Results 9

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11 We identified five themes: poor staff communication skills; problematic information  
12 exchange; language barriers; complex care needs; and, training and education needs. Below is  
13 a summary of the emerging themes and the studies included in this review.  
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### 16 Staff Communication Skills 17 18

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20 Parents are not always satisfied with how staff members disclose diagnostic  
21 information. In one study, among 45 bereaved parents, only 9 were satisfied with the  
22 communication competence of the health care staff (Davies & Connaughty, 2002). Reasons  
23 for parents' dissatisfaction included perceived lack of staff knowledge about providing  
24 emotional support, over-emphasis on a cure and treatment approach towards their child, the  
25 blunt manner of paediatricians (Browning, 2002; Ferguson, 2007), delay, denial and evasion  
26 while awaiting results (Davies et al., 2003), and unsympathetic and brief diagnostic  
27 interviews that are not always conducted in private with time to ask questions (Contro et al.,  
28 2004). Of those parents satisfied with provider communication skills, some reported open,  
29 sympathetic and direct diagnosis in private with paediatricians, who gave them time to take in  
30 the news as well as repeat and clarify information (Mack & Wolfe, 2007).  
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47 Crucial elements of good disclosure when communicating difficult news include  
48 sensitivity, empathy (Ferguson, 2007; Harnett et al., 2009), honesty, and completeness  
49 provided for both children and families (Dunlop, 2008; Harnett et al., 2009). Parents wished  
50 for positive messages that contained optimism and helped prepare children and their families  
51 for death (Wood et al., 2010). Parents who viewed their dialogue with physicians as positive  
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3 indicated that the transition of their child to hospice care was easier than they had expected  
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5 (Ferguson, 2007). Parents who viewed their dialog with physicians as negative indicated  
6  
7 feeling shocked and surprised at the news that the family should consider hospice care for  
8  
9 their child. These parents may have been more receptive to hospice care if they had been  
10  
11 included in palliative and end of life discussions earlier in their child's illness, giving them  
12  
13 time to process the information (Ferguson, 2007).  
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17 Staff communication styles are important to parents. The manner in which staff  
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19 communicated care options was most important to the parents as it reinforced their belief that  
20  
21 their child was receiving good care (Contro et al., 2004). Similarly, the style in which  
22  
23 physicians conveyed information was important: those who listened, talked in a clear  
24  
25 understandable manner and provided complete information were rated better (Hsiao et al.,  
26  
27 2007). Children and parents proposed 5 domains of physician communication deemed to be  
28  
29 highly influential in quality of palliative care received: building a relationship, demonstrating  
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31 effort and competence, exchanging information, the availability of the physician and  
32  
33 including an appropriate level of child parent involvement (Hsiao et al., 2007). Children and  
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35 parents who felt that their providers were very rushed and unresponsive experienced a barrier  
36  
37 to communication about their needs (Sloper, 1996).  
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42 A staff characteristic found to be harmful during communications with children,  
43  
44 young people and families was the technical approach of some paediatricians, which led to  
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46 depersonalisation of the experience for children and parents (Davies et al., 2003). Insensitive  
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48 care involved the poor acknowledgement of parents concerns which sometimes led to a  
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50 delayed diagnosis. . Parents whose children had just received a diagnosis for a chronic long-  
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52 term illness frequently felt that their child was seen only in the context of the illness and not  
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54 valued as an individual person or a member of a family unit (Harnett et al., 2009).  
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3 There may also be conflict between parents and staff in trying to protect children from  
4 the anxiety and distress of their diagnosis. Children and young people were more likely to  
5 want diagnostic information, whereas parents were more likely to want to protect their child  
6 from adverse information (Kunin, 1997). Similarly, some parents advocated open and direct  
7 communication with the child or young person, as long as they were had the cognition to  
8 receive such information (Monita et al., 2004) whereas others wanted to be given information  
9 first so that they could filter it (Hsiao et al., 2007). Some children and young people preferred  
10 direct communication with their physicians (Wood et al., 2010), others wanted their parents  
11 to communicate with physicians on their behalf (Palmer et al., 2007).  
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24 Open and honest communication with paediatric cancer patients is important in  
25 helping them to prepare for and cope with the overall stress of illness and treatments (Catt et  
26 al., 2005). One study found that none of the bereaved parents who discussed death with their  
27 children regretted having done so, and 27% of parents who did not discuss death with their  
28 child regretted it (Kreicbergs et al., 2004).  
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### 37 Information Exchange

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40 A cause for concern is the wide variety of professionals such as paediatricians, nurses,  
41 psychologists who provide diagnostic information and their varying levels of clinical  
42 experience. Of this group, paediatricians and psychologists are the most frequently reported  
43 (Harnett et al., 2009), but other professionals involved in early communications may include  
44 general practitioners, clinical nurses, oncologists and surgeons. The constant change of  
45 professionals interacting with the family and the child over time means frequent disruptions  
46 in care routines; parents feeling frustrated with the lack of continuity (Contro et al., 2004) are  
47 unable to build long-term relationships with providers (Contro et al., 2004; Hsiao et al.,  
48 2007).  
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3 Physicians are traditionally regarded as the primary gatekeepers of diagnostic and  
4 prognostic information and referral onto palliative and end of life care (Ferguson, 2007).  
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6 Surgeons and oncologists have primary responsibilities for explaining test results and  
7 diagnosis to patients. Clinical nurses, palliative care nurses and palliative care physicians are,  
8  
9 also important in providing effective communications with children and families. Parents  
10 reported relying more heavily on nursing professionals than physicians for information,  
11 decision-making and care planning (Davies et al., 2003). Critical care nurses are particularly  
12 important for clinician-family communications as they have many valuable insights into the  
13 progress of a disease, the family's understanding, and their wishes and needs (Sahler et al.,  
14 2006). Families in one study rated nurses' communication skills as one of the most important  
15 skills of paediatric teams, making their role particularly significant during diagnosis.  
16  
17 Furthermore, clinical nurse specialists covered the largest number of information requests  
18 identifying them as 'the thread that runs throughout the patient's care in oncology teams'  
19 (Catt et al., 2005). Palliative care multi-disciplinary teams must ensure that they are giving  
20 the same messages to patients. Nevertheless, patients and families often report inconsistency  
21 (Sahler et al., 2006).  
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39 Health care teams differ in provision and consistency of information presented to  
40 paediatric oncology patients and their families (Mack & Wolfe, 2006). Children and their  
41 families report that professionals adequately explained the likely illness trajectory at some  
42 point, but this information was not always repeated and updated to take account of the  
43 family's capacity to process and understand the information (Catt et al., 2005; Wood et al.,  
44 2009). Children and young people receiving palliative care services also reported that they  
45 received insufficient information and noted that there were poor communications between  
46 healthcare professionals. In a recent study (Wood et al., 2010), the family's main  
47 communication concern was the insufficient information presented by health professionals  
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3 about their child's condition at the point of diagnosis and throughout the child's illness. Many  
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5 turned to the internet to find more information only to find it inconsistent with what they had  
6  
7 been told. This lack of information led to additional distress during the normal course of  
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9 illness. Most families reported they wanted to know every 'worse case scenario' so that they  
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11 are aware of how long they may have left with the child and what their child might be  
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13 capable of doing in the future.. For a minority of families, repeated reminders of the  
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15 inevitable decline and eventual death of their child were too much to bear (Wood et al.,  
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17 2010).  
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21 One aspect in which training may be helpful is in enhancing the ability of staff to  
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23 tailor communication for each child and family, acknowledging that families will have  
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25 different feelings and reactions in relation to the diagnosis (Harnett et al., 2009). Those  
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27 parents and children who seem to be experiencing significant stress may need more time and  
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29 attention in order to assure good communication and to allow health care providers to assess  
30  
31 their needs and refer them to the appropriate resources (Wood et al., 2010). Family meetings  
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33 allow families and providers to discuss a plan of action. Feudtner (2007), recommends that  
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35 family members be asked to discuss their hopes, goals, decisions, and care options for the  
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37 child. In this manner, children and families can collaborate with providers.  
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#### 43 44 Language Barriers

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46 Language is a barrier that impedes children's health care services (Contro et al., 2004;  
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48 Davies et al., 2008). Communication is difficult when the patient or family members do not  
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50 speak the same language as health care staff. Among 190 registered nurses, most felt that  
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52 language or cultural differences were very influential in the level of contact they had with  
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54 patients, which ultimately had implications for quality of care (Engler et al., 2001). However,  
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56 in another study, paediatric physicians perceived culture as a communication barrier but  
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3 paediatric nurses did not (Davies et al, 2009). Physicians felt that even with a skilled  
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5 interpreter, their ability to communicate with non-English speaking families was very limited  
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7 and that some families' understanding about their child's diagnosis conflicted with  
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9 physician's beliefs and values. However, nurses felt that their role was directed more towards  
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11 offering comfort and caring nonverbally, thereby reaching across cultural or language  
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13 barriers.  
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17 Terminology can add to communication problems. Experts propose that firstly,  
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19 phrases need to be more sensitive such as using 'allowing death to naturally occur' instead of  
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21 'withdrawing or withholding treatment' (Renea et al., 2010). Secondly, children and families  
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23 need to be assured that 'palliative care is active involvement and not passive withdrawal'  
24  
25 (Wood et al., 2010). Thirdly, medical terminology should be comprehensible to parents  
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27 (Davies et al., 2003). Nonetheless, parents report that clinical practices and sensitivity  
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29 supersede terminology.  
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### 35 36 Complex Care Needs

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39 Staff report that at times during the course of providing clinical feedback to children  
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41 and families, despite their best efforts, conflicts arise (Feudtner, 2007). Experts have explored  
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43 the issue of challenging and aggressive behaviours in adult palliative care (Hynson et al.,  
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45 2001; Karen & McQuillan, 2005; Tuffrey et al., 2007), however, this has not been replicated  
46  
47 in palliative care of children and young people. Staff might benefit from advanced  
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49 communications training perhaps using role play, to enable them to understand how  
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51 challenging behaviours from young people arise and how to appropriately manage them.  
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56 Overcoming communication difficulties between staff, children, young people and  
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58 families with both palliative care needs and learning disabilities is also perceived as a barrier.  
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3 Health professionals need to adopt a more collaborative approach to care (ACT, 2009) and  
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5 should share their expertise with parents and others involved in the child's care (i.e., staff  
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7 from special education and social care) (Kerzman & Smith, 2004). This collaborative  
8  
9 approach helps to establish clear lines of communications with children and young people  
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11 and enables them to receive the best care. For those children who are unable to communicate  
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13 verbally or in writing, an informal language can be utilised by maximising the sensory  
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15 resources available to the child or young person (Tuffrey et al., 2007).  
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### 18 19 Training and Education Needs 20

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22 There is limited educational preparation regarding communications in palliative care  
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24 for children and young people (Back et al., 2007; Davies et al., 2008; Ferguson, 2007; Sheetz  
25  
26 et al., 2008). Health care professionals who must break bad news to children and families  
27  
28 often find the process difficult due to the lack of available guidelines, particularly with  
29  
30 regards to paediatric patients (Sheetz et al., 2008). Paediatricians must be trained to be better  
31  
32 at identifying with and communicating proactively with children and families.  
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36 The Improving Outcomes Guidance (National Health Service Executive, 2004) makes  
37  
38 explicit recommendations about communication between healthcare professionals and  
39  
40 patients but there is little evidence available about the advantages and disadvantages of this  
41  
42 approach within palliative and oncology care for children and young people (Catt et al.,  
43  
44 2005). In a focus group for paediatric health care professionals, 93.3% expressed the need for  
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46 additional communication skills training and 80.7% felt they required specific training for  
47  
48 disclosing diagnostic information to children and their families (Harnett et al., 2009).  
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51 Communication training should focus on broadening the repertoire of available  
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53 communication skills rather than repeatedly performing the same skill (Back et al., 2007).  
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## Discussion

From our results, we identified 11 articles reporting on communication barriers within palliative care for children and young people and four others reported on communication barriers specifically during diagnostic disclosure. In the UK, there has been considerable effort to improve palliative care among adult patients however, there has been limited exploration into the complex communication barriers explicitly relating to the children's palliative care pathway, particularly during disclosure of initial diagnosis.

Children with palliative care needs and their families rely on good communication between themselves and professionals. Our results highlighted that professionals' interpersonal communication skills needs improvement. This may be due to limited training opportunities that health care professionals have to develop their skills for communicating effectively with dying children and their families. Further, the emergent themes imply that a majority of communication barriers arise in paediatric palliative care due to the lack of staff knowledge, sensitivity and competency regarding provision of appropriate emotional support for children and families. Professional staff also lack guidance on how best to manage the conflicting goals and values that can arise between themselves and families, particularly during the critical point of diagnostic disclosure. A strong message from the review was that there is limited availability of formal guidelines around provider communications with children and families and those that are available are not being effectively translated into knowledge and skills amongst staff.

Recommendations for improving communication and emotional support for families are to combine clinical skills training with an empathetic understanding of the needs of children, young people and families. Dedicated communication training is also indicated. A

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3 component of the training should focus on identifying individual family's needs through  
4 discussions with the family as early as initial diagnosis. Where appropriate discussions  
5 should include the level of involvement and direct communications the child and family are  
6 comfortable with in order to address any underlying conflicts and beliefs. Training should be  
7 person and patient centred in order to allow professionals to acknowledge and respect the  
8 child and family first and the illness second. Investment is thus needed to standardise this  
9 training and apply it to all levels of staff involved in the paediatric palliative care pathway to  
10 ensure consistency and quality of communications between staff and with families.  
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21 Our review highlighted that practitioners need to work more openly, proactively and  
22 collaboratively with families. Early and honest communications with families about palliative  
23 and end of life care options could offer parents a greater sense of mental preparation, hope  
24 and control regarding their dying child's quality of life. It is vital that families needs are  
25 understood and addressed and this involves the inclusion of all their views at disclosure of  
26 diagnosis. If staff perceive that a family is facing communication challenges with the health  
27 care team or is receiving mixed messages from different staff members, a consultation  
28 meeting should be coordinated between the clinical team and family.  
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40 The results indicate that the styles and techniques of paediatric palliative care staff are  
41 important for effective communication although they may be influenced by the type of illness  
42 the child has. It is likely that the communication styles employed when disclosing a diagnosis  
43 for a rapidly progressive disease will differ to that employed for a chronic long term disease.  
44 It is recommended that this should be a key area of investigation for future research aiming to  
45 identify factors to facilitate effective communications according to specific family  
46 circumstances. A serious concern is that the children and young people's perspective in the  
47 process of disclosure diagnosis communication paediatric palliative care is sparse and much  
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3 of the research was dated. New research from the perspective of children and young people  
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5 would help to significantly advance knowledge for practice.  
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52 \*Davies, R., Davis, B.. & Sibert, J. (2003). Parents stories of sensitive and insensitive care  
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54 by paediatricians in the time leading up to and including diagnostic disclosure of a  
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3 life-limiting condition in their child. *Child Care, Health and Development* 29(1), 77-  
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