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An evaluation of the educational support for teachers who teach children with life limiting illness in schools

Abstract

There are increasing numbers of children living with life limiting illnesses in mainstream schools. The aim of this literature-based study was to evaluate the current provision of educational support for teachers who are teaching these children in schools. An international literature search produced 23 papers published between 2005 and July 2010 which concerned children with life limiting illness in relation to education in mainstream schools. The analysis identified that the needs of children with life limiting illnesses are not being well met, and there appears to be little evidence of educational support for teachers. The paper concludes that schools need to work with both the medical and social models of health/disability in order to meet the needs of children with life-limiting illness. There is some consensus that the way forward needs to include multidisciplinary working within an ecological approach that supports home, schools and the health services working together. Only one paper reported an evaluation of such an intervention. There is a need for more research, evaluation and dissemination about the experience of living with a life-limiting illness in mainstream schools and related interventions, and for this to inform professional education and the co-ordination of education, health and home systems.

An evaluation of the educational support for teachers who teach children with life limiting illness in schools

Introduction

Thanks to the survival of low weight babies (Cochrane et al, 2007; Wilson-Costello et al, 2005) and improvements in medical knowledge, technology and treatment, more children are surviving and living with life limiting illness compared to previously (Stam et al, 2006). For example children born with HIV are living healthier and longer lives thanks to antiretroviral therapy and better perinatal management (Kaplan et al, 2000). Most children with cystic fibrosis (Blair et al, 2001; Cans, 2000) and cancer, including leukaemia, can now expect to live into adulthood (Gatta et al, 2002; Gatta et al, 2005). Sick children spend less time in hospitals and more time receiving treatment and recovering at home. The model of the hospital school is being replaced by one which needs to provide children's education at home and support successful re-integration back to their own school (St Leger and Campbell, 2008).

In 2009 the United Nations Educational, Scientific and Cultural Organization (UNESCO) published Policy Guidelines on Inclusion in Education which, they explain, build on the rights for all children, including those suffering illness and poor health, to receive education as set out in the United Nations Convention on the Rights of the Child (1989), the Education for All by 2015 goals, the Millennium Development Goals and Article 24 of the Convention on the Rights of Persons with Disabilities (2006). Some countries, such as Ireland, Iceland, France, Poland and Finland explicitly include pupils with chronic illness into their legal definitions of children with special educational needs, and for whom support via national policies is in place (European Agency for Development in Special Educational Needs, 2010). In England the law states that children who can not attend school due to an illness that necessitates prolonged or recurring periods of absence from school should be provided with access to an education similar to that available at school, and school governors need to ensure that a policy is in place that incorporates the close liaison of teachers, hospital and home (DfES, 2002; DfE, 2010).

The aim of this literature-based study was to evaluate the current provision of educational support for teachers who are teaching children with life limiting illness in schools. Life limiting illnesses in children can include (i) conditions for which curative treatment is feasible but can fail such as cancer and irreversible organ failure (ii) conditions requiring long periods of intensive treatment, but premature death is still possible such as cystic fibrosis (iii) progressive conditions without curative treatment such as Batten's disease and (iv) conditions with severe neurological disability which might deteriorate unpredictably such as those with severe multiple disabilities following brain or spinal cord injuries (ACT/RCPCH, 2003).

Specifically, the literature review aimed to answer the following questions:

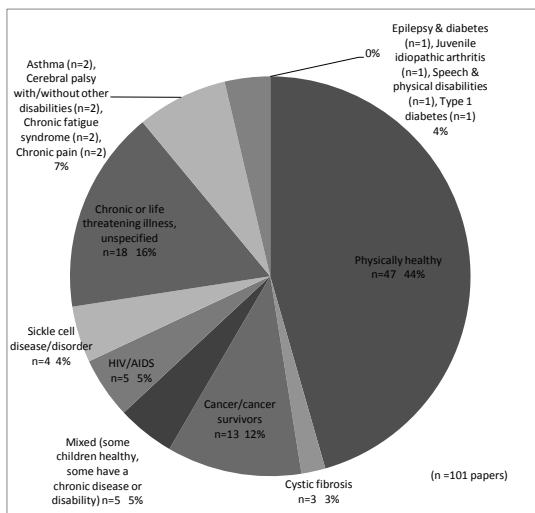
- What are the needs of children who have life limiting illness, and their families, when the child is in school?
- What are the needs of teachers who are teaching children with life limiting illness?
- What educational support is currently available for teachers who are teaching children with life limiting illness?
- How well does the educational support meet the needs identified within the context of the literature reviewed?

Search strategy

A search was carried out between February and July 2010 for academic journal articles across nine electronic data bases: British Nursing Index, CINAHL, MEDLINE, Oxford Journals, PubMed Central, ASSIA, British Education Index and the Paediatric Nursing database. The inclusion criteria comprised combining three search terms: child/children/children's, young people, adolescents, paediatric OR pediatric, WITH chronic illness/ condition, life-limiting illness/condition, palliative, cancer, liver failure, renal failure, oncology/oncological, HIV, AIDS, cystic fibrosis, muscular dystrophy OR cerebral palsy WITH education, learning, education, school/schools, teaching, teacher(s), absenteeism, attainment OR academic. Papers were excluded if they were published earlier than 2005, about settings other than mainstream schools and if they were reporting on the experiences of others close to children, but not the children themselves, such as the experiences of the parents of a child with a life-limiting illness.

Results

Figure1 Health issues emerging from the initial search strategy



A total of 101 papers were identified, of which 46% were papers about primary prevention and healthy children (see Figure i). 71% of these were about HIV/AIDS prevention, and the rest concerned the prevention of cervical cancer, obesity or substance misuse; the promotion of mental health or physical activity; school policies and children’s views of disability. The 101 papers reported on interventions or literature relating to 29 individual countries covering all continents, and three concerned more than one country. 79% reported primary research.

Table 1 Categorisation of the health-related descriptions attributed to the children or young people in the papers

Life limiting	Not life limiting
Brain tumour survivors	Chronic disease (not specified)
Cancer	Chronic fatigue syndrome
Cancer survivors	Chronic illness (not specified)
Cerebral palsy	Chronic illness (asthma, diabetes, obesity)
Cerebral palsy and other disabilities	Chronic illness/disability
Chronic illness (usually cancer)	Chronic pain
Chronic or life threatening disease	Diabetes type 1
Cystic fibrosis	Epilepsy and diabetes
HIV	Juvenile idiopathic arthritis
HIV/AIDS	Sickle cell disease/disorder
Leukaemia	Speech and physical disabilities
Life threatening illness	
Life-limiting or life threatening conditions	

The remaining 54 papers (54%) concerned children with chronic or life limiting illnesses. Of these 31 (57%) were defined as not being life-limiting, or that the paper did not clearly state the type of chronic illness. Twenty three (43%) were defined as being life-limiting. The health-related descriptions attributed to the children or young people, and how they were classified, are shown in Table 1.

Table 2 The 23 papers relating to life limiting illness in schools

Asprey, A. & Nash, T. (2006). The importance of awareness and communication for the inclusion of young people with life-limiting conditions in mainstream school and colleges. *British Journal of Special Education*, 37(1), 5-21.

Breen, M., Coombes, L. & Bradbourne, C. (2009). Supportive care for children and young people during cancer treatment. *Community Practitioner*, 82(9), 28-31.

Davies, R. (2006). The potential of integrated multi-agency care pathways for children. *British Journal of Nursing*, 15(14), 764-768.

Evans, D. (2008) News around the world. *Gifted Education International*, 24 (2/3), 357-361.

Fielden, L.S., Heckter, G.E. & Chapman, A. et al. (2006). Growing up: perspectives of children, families and service providers regarding the needs of older children with perinatally-acquired HIV. *AIDS Care*, 18(8), 1050-1053.

Gorin, S. & McAuliffe, P. (2009). Implications of childhood cancer survivors in the classroom and the school. *Health Education*, 109(1), 25-48.

Greyling, L., de Lange, N. & Leslie, G. (2005). What do we know about the perception educators have of HIV/AIDS and its impact on the holistic development of adolescent learners? *International Journal of Adolescence and Youth*, 12, 29-48.

Grinyer (2007). The biographic impact of teenage and adolescent cancer. *Chronic Illness*, 3, 265-277.

Harris, M.S. (2009). School reintegration for children and adolescents with cancer: The role of school psychologists. *Psychology in Schools*, 46 (7), 579-592.

Huang, C., Sugden, D. & Beveridge, S. (2009). Children's perceptions of their use of assistive devices in home and school settings. *Disability and Rehabilitation: Assistive Technology*, 4 (2), 95-105.

Kendall, N. & O'Gara, C. (2007). Vulnerable children, communities and schools: lessons from three HIV/AIDS affected areas. *Compare*, 37(1), 5-21.

Mayer, D.K., Parsons, S.K., Terrin & N., Tighiouart, H., Jeruss, S., Nakagawa, K., Iwata, I., Hara, J., & Saiki-Craighill, S.S. (2005). School re-entry after a cancer diagnosis: physician attitudes about truth telling and information sharing, *Child: Care, Health & Development*, 31 (3), 355-363.

Palmer, S.L. & Leigh, L. (2009). Survivors of pediatric posterior fossa tumors: cognitive outcome, intervention and risk-based care. *European Journal of Oncology Nursing*, 13, 171-178.

Rózsagegyi, T. (2008). Training and collaboration: implications of feedback from early-years practitioners in England following in-service training on cerebral palsy. *Recent Advances in Conductive Education*, 7(1): 17-21.

Savage, E., O Riordan, A. & Hughes, M. (2009). Quality of life in children with acute lymphoblastic leukaemia: a systematic review. *European Journal of Oncology Nursing*, 13, 36-48.

Sherr, L., Mueller, J. & Varrall, R. (2009). Evidence-based gender findings for children affected by HIV and AIDS – a systematic overview. *AIDS Care*, 21 (S1), 83-97.

St Leger, P. & Campbell, L. (2008). Evaluation of a school-linked program for children with cancer. *Health Education*, 108(2), 117-129.

Stam, H., Groothuis, M.A. & Last, B.F. (2005). The course of life of survivors of childhood cancer. *Psycho-Oncology*, 14, 227-238.

Stam, H., Hartman, E.E., Hartman, M.A., Deurloo, J.A., Groothoff, J. & Groothuis, M.A. (2006). Young adult patients with a history of pediatric disease: impact on course of life and transition into adulthood. *Journal of Adolescent Health*, 39, 4-13.

Upton, P. & Eisner, C. (2006). School experiences after treatment for a brain tumour. *Child: Care, Health & Development*, 32(1), 9-17.

Wicks, E. (2007). A patient's journey: cystic fibrosis. *BMJ*, 334, 1270-1271.

Wiener, L., Battles, H., Bernstein, D., Long, L., Derdak, J., Mackall, C.L. & Mansky, P.J. (2006). Persistent psychological distress in long-term survivors of pediatric sarcoma: the experience at a single institution. *Psycho-Oncology*, 15, 898-910.

Wu, M., Hsu, L., Zhang, B., Shen, N., Lu, H. and Li, S. (2010). The experiences of cancer –related fatigue among Chinese children with leukaemia: a phenomenological study. *International Journal of Nursing Studies*, 47, 49-59.

Table 2 lists the 23 papers which concerned children or young people with life-limiting illnesses. Six of these were based on work in England, one concerned the whole of the UK, four were based in the USA, two in each of the Netherlands and South Africa, one in each of Australia, Canada, China, Ireland, Malawi and Taiwan. One paper reported on work relating to both the USA and Japan, and one concerned children in various countries. Out of the 16 research papers, eight were relevant to children and young people in all schools, four to both secondary and primary, two to secondary, one to primary school, and one to primary, secondary and further education. The seven literature-based papers comprised four which were relevant to all schools, two which concerned both primary and secondary schools, and one did not specify the type of school.

1. What are the needs of children who have life limiting illness and their families, when the child is in school?

Children with life limiting illnesses, who are able to attend school, are likely to have a wide range of physical impediments to their learning. Children undergoing cancer treatment might experience altered taste, a loss of appetite and constipation, and they are particularly vulnerable to infections such as measles and chicken pox (Breen et al, 2009). A number of childhood cancers can lead to hearing loss, cataracts, osteoporosis, impaired growth as well as oral and dental malformations (Gorin and McAuliffe, 2009). Two years after receiving treatment for a brain tumour, children can still have a range of neurological problems including ataxia, hemiparesis and visual, auditory and speech impediments (Upton and Eiser, 2006). A child with acute lymphoblastic leukaemia can undergo treatment which can lead to nausea, vomiting, infection, fatigue, emotional and behavioural problems, and long-term impaired intellectual function (Savage et al, 2009). Gorin and McAuliffe (2009) suggest that those children with brain tumours or acute lymphocytic leukaemia are the most likely to experience reduced neurocognitive functioning after treatment, and girls seem to have more problems than boys. Palmer and Leigh (2009) explain that children who have survived brain tumours (pediatric posterior fossa tumors) can suffer an overall decline in their intellectual ability and academic achievement which seems to be linked to a slowing down of information processing, impaired memory and difficulties with sustaining attention.

Fatigue is a significant consequence of childhood cancer and its treatment (Breen et al, 2009; Gorin and McAuliffe, 2009) and it was the subject of Wu et al's (2010) focus groups, where the Chinese children with leukaemia discussed what made them tired. The physiological factors included having chemotherapy, pain, fever, hunger, nausea and disturbed sleep; the psychological factors included feelings of anxiety, stress, melancholy, being obliged and repressed by parents who seemed to decide everything for them; and the situational ones included travel, noise, light, too much or too little long-term activity, travel and a busy school life. The children explained that their fatigue affected their ability to think, to work out problems and to remember, in summary, it seriously affected their ability to learn and keep up with their peers. In turn, this had negative effects on their self-concept and self-confidence.

Inevitably, children undergoing treatment need to be absent from school. In one English study of school experiences after treatment for a brain tumour (Upton and Eisner, 2006), school absence relating to the illness and treatment, was recorded as being between two weeks and two years, with a mean length of absence being 3.8 months. Hospital appointments took up an average of 5.1 days per year, with the range extending to 66 days. In a retrospective study of American adults who had undergone cancer treatment in their childhood or youth, 24% reported that they had experienced difficulty keeping up with school or job requirements after finishing their treatment, and many recalled having lengthy periods away from school and peer activities as being particularly stressful (Wiener et al, 2006). In a study of 40 British children who had survived brain tumours, many were struggling with literacy and numeracy (Upton and Eisner, 2006). This was thought to be partly due to school absences, as even those without brain illness can perform less well academically if frequently

absent, and the parents thought that through absence their children had missed 'basic building blocks' of learning.

Children who are undergoing treatment for cancer might experience particular challenges at school because of changes to their appearance such as weight loss, hair loss due to chemotherapy or weight gain due to taking steroids (Breen et al, 2009). In one English study with young people (Grinyer, 2007), some respondents reported being subject to intolerance and abuse because of wearing head covering to conceal their baldness. This was either because of policies that forbade head covering, or because passers-by interpreted baldness as being symbolic of defiant youth culture. Some of the Taiwanese children with cerebral palsy in Huang et al's study (2009) reported feeling uneasy and inferior to peers because of their asymmetric movement and functional limitations. Children with cystic fibrosis or chronic renal failure might enter puberty later than average (Stam et al, 2006). Changes or differences in appearance directly threatens children and young people's self-esteem, self-belief and confidence, which in turn affects their confidence to form relationships and feel socially accepted (Gorin and McAuliffe, 2008; Grinyer, 2007).

Canadian children who were HIV positive reported that they were reluctant to disclose their HIV status because they had experienced being ostracised, or anticipated losing friends (Fielden et al, 2006). This social stigma was also reported by Chinese children with leukaemia (Wu et al, 2010) and Taiwanese children with cerebral palsy (Huang et al, 2009). Sick children might also witness the death of close friends who share their illness (Wicks, 2007). A case study in Malawi discussed how a school was cancelled at least once a week due to funerals resulting from AIDS related death (Kendall and O'Gara, 2007). The, "... vulnerable children were, in short, a present but officially invisible population in the school" (p.10) as their plight was never openly discussed. The consequence of the physical, psychological and social hardship combined is that children coping with a life-limiting illness tend to have smaller social networks, less peer support, less peer acceptance and consequently they can be lonely (Upton and Eiser, 2006).

Adolescence is argued to be a particularly significant life stage because the illness interferes with the process of transition to adulthood, and the formation of an adult identity. While others are leaving school, home, gaining jobs and starting to be independent and making life-changing decisions which will shape their future, these young people not only have to relinquish their own plans, but they witness their friends progressing to the next stage, leaving the young person feeling isolated (Grinyer, 2007; Wiener et al, 2006). The distress from the illness experience appears to continue into adulthood (Wiener et al, 2006; Palmer and Leigh, 2009). Dutch adults with a history of chronic or child life limiting illnesses remembered having fewer friends and participating less in risk taking behaviour, during secondary school, compared to peers (Stam et al, 2006). As adults, they report having achieved significantly fewer milestones, or doing so at an older age, compared to their peers, across the domains of autonomy, social and psycho-sexual development (Stam et al, 2005; 2006). An American study which investigated the long term effects of having childhood cancer (Wiener et al, 2006) characterised the 34 adult respondents, who were asked to discuss their life histories, as having significant persistent psychological distress. Twelve per cent met the diagnostic criteria for post traumatic stress disorder and 77% scored in the clinical range of the Brief Symptom Inventory.

The papers reviewed here suggest that key stressors include the physical and emotional challenges of the illness and treatment such as fatigue, the consequent absence from school and the loss of confidence emanating from concerns about appearance and peer and social acceptance. Together these make learning, 'keeping up' and achieving at school a significant challenge. As one teenager reported, "I don't think they [the school] wanted to waste their money on the GCSEs for me because they thought I was going to fail (Ricky diagnosed with leukaemia at age 15) (Grinyer 2007 p.270). It is also emotionally and physically exhausting for the child's parents, particularly the mother who often takes on the majority of the child's care (Davies, 2006). Siblings might also be experiencing feelings

of insecurity, anxiety and perhaps jealousy (Breen et al, 2009). So it is not only children, but also their families, who need time to recover from treatment and regain their energy before educational demands are made on them (St Leger and Campbell, 2008).

2. What are the needs of teachers who are teaching children with life limiting illness?

Much research carried out with parents, children and teachers points to the importance of teachers having a good understanding of an individual child's medical needs (Asprey and Nash, 2006; Rózsagegyi, 2008; St Leger and Campbell, 2008; Gorin and McAuliffe, 2008). Asprey and Nash (2006) explain that the medical model of disability, which focuses on the individual child's condition and their impairments, has been rejected in guidance documents about education in England in favour of a social model of disability which places an emphasis on the structural and cultural aspects of the school and the beliefs and actions of the teachers to accommodate all children's needs. However, the findings from their study suggested that schools and colleges were following neither a medical nor a social model, and so the children's needs were not being addressed in any coherent way. Asprey and Nash carried out interviews with 46 parents of children and young people with life-limiting illness in England and found that a third thought that the school or college did not have adequate knowledge, and some explained that even though they had provided information, they did not think that it had been fully understood by the teachers. For example teachers need to be aware of potential risks of infection for the child (Breen et al, 2009). Asprey and Nash (2006) suggest that teachers who are teaching children with life-limiting illnesses, firstly, need to be made much more aware of children's medical conditions, their consequences and the obstacles that they meet within the educational system. Thereafter, teachers need to be prepared to tailor a child's education according to their cognitive, social and emotional developmental stage, all of which can be affected by illness, absence or medical treatment, and to the child's stage of treatment such as taking into account planned absences and physical or psychological challenges (Gorin and McAuliffe, 2008).

Teachers need to understand that having access to normal social activities, including attending school and maintaining contact with peers are essential for a child's quality of life (Davies, 2006; Stam et al, 2005; 2006; Breen et al, 2009). Teachers might need to provide factual information about a child's illness to others in order to facilitate easier re-integration of a child back among his/her school peers (Gorin and McAuliffe, 2008) and to prevent stigmatisation (Fielden et al, 2006). Teachers also need to consider providing support for the siblings of children who are very sick (Breen et al, 2009). Kendall and O'Gara's research (2007) in Malawi showed that despite high death rates of school children and their families due AIDS related illnesses, the teachers did not discuss AIDS at committee, parent-teacher or internal school planning meetings. Teachers' comments and behaviour suggested that they did not feel a responsibility for tracking vulnerable children's attendance or wellbeing, and they kept no records relating to children who were sick and never openly discussed the illness or the funerals which took place most weeks. The teachers taught facts about HIV prevention in a detached way with no classroom discussion or application to the immediate situation. This example might suggest that the teachers were in denial and ill-equipped to deal with the massive emotional impact of the situation, or it might suggest that the teachers thought that to do so would have interfered with a wish to present school as a place of much needed 'normality'. Culture was also highlighted by a study comparing American and Japanese children's return to school after a cancer diagnosis (Mayer et al, 2005). This showed that the Americans emphasised open dialogue and medical liaison with schools, whereas the Japanese were more likely to keep information from both the child and the school. These studies provide a reminder to be sensitive to local cultural history and understandings when examining the needs of teachers.

Parents sometimes report difficulties with communication between themselves and teachers about their sick child. Asprey and Nash (2006) report that in England if a child does not have a Statement of Special Educational Needs the parents can feel that there is no particular teacher with whom they can liaise about their child. Consequently some parents want teachers to encourage children to complete diaries as a way of keeping teachers aware of what was happening to the child, such as emergency hospital visits or treatment, when out of school. Mothers of children with cerebral palsy in Taiwan (Huang et al, 2009) and England (Rózsagegyi, 2008) want better communication with teachers to ensure that they have appropriate resources and the child's practice with assistive devices such as wheelchairs or walkers is continued whilst at school. Some English parents are concerned that their communication with teachers is reduced when their sick child reaches 16 years old and so begins to be accorded the confidentiality given to adults (Asprey and Nash, 2006).

The papers reviewed for this study suggest that relying on individual parents to communicate their child's needs to individual teachers in the hope that this teacher will be able to meet these needs is inadequate and wider, culturally sensitive, support systems for both are needed. Much is written about the need for teachers to work more closely with family and the wider multi-disciplinary team. Wicks' (2007) autobiographical account of living with cystic fibrosis notes that there appeared to be no dialogue between health and educational professionals when she was at school. Return to school after medical treatment has been found to be easier if teachers have kept in touch with family and/or with hospital-based teachers (Breen et al, 2009; Harris, 2009). The evaluation of the Australian 'Back on Track' programme demonstrated that teachers need to be motivated to want to invest in on-going communication with children, families and medical staff because it takes time and a strong commitment to attend meetings, obtain information, to work flexibly to accommodate the individual child's needs and to be willing to learn new communication skills for example through information communication technology (St Leger and Campbell, 2008).

3. What educational support is currently available for teachers who are teaching children with life limiting illness?

Out of the eight papers that contained information about the educational support for teachers, only one discussed the provision of an educational programme for teachers (Rózsagegyi, 2008) and four argued that particular people might play a useful supportive role. In the USA, Palmer and Leigh (2009) and Harris (2009) propose the school psychologist as someone who could carry out objective assessments of the child's academic performance and cognitive skills, such as memory processes, which can complement the child's own self-reported abilities (Palmer and Leigh, 2009). The school psychologist can become an advocate for the child and a key source of information and support for the teachers (Palmer and Leigh, 2009). Mayer et al, (2005) cites the role of American doctors who frequently inform key school officials, including teachers and the child's peers, about a child returning to school after a cancer diagnosis and thus facilitates appropriate preparation. In England, Breen et al (2009) explain how hospital-based teachers can liaise with the child's teachers at school and can play a key role in facilitating a smooth transition back to school. In addition professionals, such as cancer outreach nurses, community children's nurses and/or school nurses can visit schools, preferably together, to provide information about the child's health needs to teachers. They can also advise about physical and psychological needs relating to other children, such as cases of infectious diseases in school or teasing. Asprey and Nash (2006) report that specialist nurses can train teaching assistants about the needs of the children, but for long-term benefit, the nurses need to be able to attend regularly.

Six papers proposed models or pathways, citing the importance of the multi-agency team to provide coherent information, communication, support and care (Breen et al, 2009; Davies, 2006; Harris, 2009; Goren and McAuliffe, 2009; Palmer and Leigh, 2009; Asprey and Nash, 2006). The Australian Back on Track programme emphasised the importance of teachers fostering improved links with

local, regional, early childhood and health departments in order to better understand the children's needs and to obtain the necessary funding (St Leger and Campbell, 2008). Harris (2009), Davies (2006), Gorin and McAuliffe (2009) and Palmer and Leigh (2009) call for schools to work with an ecological approach to support children and young people with cancer. This approach emphasises the interrelationships between the complex ecosystems of home, school (teachers and peers) and hospital/health services. It emphasises that the child with life limiting illness affects the environment and the environment affects the child. This dynamic relationship influences, and is influenced by, the wider neighbourhood, friends, local services and so forth. For example Harris's (2009) eco-triadic model identifies an educational consultant, who is recommended to be a school psychologist, whose role is to co-ordinate the smooth transition of a child from hospital to school. The model includes checklists of questions that the consultant could ask of the hospital, home (including the child) and school before, during and after school reintegration following treatment. In the UK, the multi-agency Integrated Care Pathway recommends social workers or community children's nurses to co-ordinate services (Davies, 2006).

The papers suggest that most educational support for teachers needs to come from learning from, and working alongside, others. There were many examples of what teachers could and should do, but only one example of actual educational support taking place with the teachers' evaluation (Rózsagegyi, 2008).

4. How well does the educational support meet the needs identified within the context of the literature reviewed?

The six papers that discussed models or pathways were based on research that has analysed the unmet needs of children, families and teachers rather than empirically evaluated strategies. Gorin and McAuliffe (2009) and Palmer and Leigh (2009) note that at the time of their study they were unable to find any studies reporting on systematic research of ecological approaches towards supporting childhood cancer. This lack of evidence was also identified by Davies (2006) who suggests that any variance to the pathways described in the multi-disciplinary Integrated Care Pathways needs to be documented and used to review and update the pathway of care. She also suggests the inclusion of action research as part of this process. Gorin and McAuliffe (2009) outline a detailed research agenda based on their model. They suggest that research studies need to examine the socio-demographic, family, peer and disease-related factors that promote successful survival and reduced morbidity and mortality. They also suggest the utilization of evidence-based guidelines that have already been produced such as The Children's Oncology Group (www.survivorshipguidelines.org/pdf/EducationalIssues.pdf), and provide their own list of practical school-based interventions designed to address the areas of difficulty that have been found through research, including fatigue, the pace and volume of the academic work, memory, organisation of work, hearing loss and social isolation.

If ecological models are to work, they will need to be supported by well trained professionals. Rózsagegyi (2008) evaluated a Conductive Education programme, designed to support professionals working with children with cerebral palsy and other physical disabilities. The evaluation found that the commonest reason for attending the programme related to the professionals' perceived deficiencies, in both depth and breadth, of their training to date. Specifically, Rózsagegyi identified that practitioners need more education about the condition, adapting and designing learning environments and about resources to support educational and out-of-school activities. Harris (2009) calls for the training of school psychologists to enhance their support of children and adolescents with cancer because, as Gorin and McAuliffe (2009) explain, general psychological testing tends to rely on measures of IQ and achievement, which will inadequately identify impediments to memory or social and emotional functioning. These require different assessments, and teachers need to be prepared to offer tailored educational programmes and support which take into account academic,

psychological and social needs, and these in turn need to be evaluated. Evans (2008) reports on her intention to carry out an evaluation of a course 'Supporting children and adults living with HIV/AIDS' in the South African Tree-Reach Research Project which is designed to provide the thinking skills and problem solving strategies that early years practitioners need in order to assist vulnerable children and orphans and to enable them to become the agents of change within communities. No papers were identified which reported on the impact of educational interventions for professionals who might support children with life-limiting illness in school settings.

St Leger and Campbell's (2008) evaluation of the Australian Back on Track programme was the only paper found that evaluates an intervention designed to bring together home, hospital and school. The programme was funded by the Bone Marrow Donor Institute and coordinated by the Royal Children's Hospital Education Institute, Victoria. It aimed to provide educational and social support to children with cancer who experienced prolonged absence from school, to foster collaboration between the children, families, hospital and wider health networks, to empower schools to meet the educational and support needs of the children and to use Information and Communication Technologies. The evaluation identified that the programme: created extra work for teachers, especially related to the information and communication technology (ICT) related activities, the curriculum and the need for learning templates; highlighted the importance of face to face and phone contact between school, family and children; provided welcome information for the staff about cancer and how it affects families; highlighted the importance of all parties being fully motivated and committed to the programme; and demonstrated that the programme needed to be flexible and allow for children being ill. The evaluation highlighted the need for wider support in term of ICT equipment, permissions and skills; the need for school to develop formal links with local, regional and early education departments and the need for both the health and education sectors to support the costs of the programme.

Conclusion

Among the westernised industrial nations, there has been much criticism of the medical model of health and disability because it has been used to stigmatize and alienate individuals, putting the emphasis on their need to change and adapt to the perceived norms of society. Consequently the pendulum has swung to emphasising the social model which fosters social and environmental change, to demonstrate the acceptance and inclusion of all (Barry and Yuill,2008). Yet each has its limitations. The medical model does not consider the significant influence of the environment and the social model does not sufficiently consider the unique, specific needs of each individual child. Children with life-limiting illness are falling through the gap.

Children with life-limiting illnesses are physically, emotionally, mentally and socially vulnerable. The medical model focuses on the illness and how it limits the child. Children and their parents are saying that they need teachers to know and understand the child's symptoms and how the treatment regimes affects their learning and psycho-social aspects of their lives. Only when teachers have this understanding can they tailor the individual child's education to their needs, such as keeping in contact while the child is away from school, adjusting the teaching and learning strategies and modifying the curriculum. With this understanding, the teacher can also play a vital part in supporting the child's relationships with other staff and peers. Teachers need to be the advocate of the child by helping other children to be understanding of a sick child's limitations and needs. In this way, the medical model is a necessary part of supporting these children. Health professionals, psychologists, parents and others can provide teachers with education and support. The well informed teacher is best placed to consider how the school environment and systems can become sufficiently flexible to accommodate the children's needs. The social model focuses on removing barriers within the physical and social environment that might limit children with life-limiting illness. This includes educating school personnel, considering the geography and pace of the school

environment, providing access to appropriate aids, technology and staff. The findings suggest that both the medical and social models are needed to address the needs of children with life-limiting illness.

Ecological models seek to acknowledge the real-life interplay of the medical and social models by focussing on the dynamic systems within which they operate, such as the home, school and health service. They explicitly incorporate the role of mediation, co-operation and communication, through identifying who (e.g. educational consultant), how (e.g. information and communication technology, pathways of care) and where (e.g. home, school, culture). For these principles to flourish, they need to be incorporated into teacher education and inter-professional learning that includes teachers. UNESCO (2009) has also identified the need to reform teacher education programmes to include providing teachers with the pedagogical capacities to practice inclusive education with diverse children, and the training of all community professionals who need to support inclusive education.

This study found that educational support for teachers appears to be almost absent, or rarely reported in published articles, as are teachers' own views about teaching children with life limiting illnesses. The review was limited by the exclusion of papers which discussed children's chronic illness but did not identify to what degree these included life-limiting conditions. The majority of the papers related to western, developed countries of the world, mostly from the UK, USA and Europe. This study, like Gorin and McAuliffe (2009), concludes that there is a need for more research, evaluation and dissemination about the experience of living with a life-limiting illness in school settings, and for this to inform professional education and ultimately improve the co-ordination of the education, health and home systems.

In the meantime, it can not be left to struggling families to take the initiative. More individual teachers need to pro-actively ask for information and support from parents, health care providers, health charities, credible internet sites, teacher education providers and teacher resources so that they can provide the best informed educational and school experience for children with life-limiting illnesses.

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