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Teachers communicating about Life-Limiting Conditions, Death and Bereavement

Abstract

The number of children with life-limiting or life-threatening conditions in England is double what it was at the millennium. These conditions include cystic fibrosis, cancer, organ failure and severe neurological injuries. The Teaching for Life project aimed to explore the needs of teachers working in English schools in relation to working with children with life-limiting or life-threatening conditions through. Ninety teachers completed a questionnaire and 38 completed individual and group interviews. About half the teachers interviewed had experience of working with children with life-limiting or life-threatening conditions, and half did not. The teachers expressed a number of anxieties about coping with illness, death and bereavement. They described difficulties in communicating with parents, children and health professionals. They worried about maintaining their professional role whilst needing to contain their own emotions and the emotions of others, within school cultures that did not feel supportive. The paper concludes that policies and practices that seek to support children with medical conditions need to acknowledge the weight of responsibility for teachers. They need to articulate with a whole school approach that protects and promotes teachers' emotional wellbeing.

Teachers communicating about life-limiting conditions, death and bereavement

Introduction

It is estimated that there are between 25 to 32 per 10,000 children and young people living with a life-limiting or life-threatening condition in England (Fraser et al. 2011). The numbers have doubled since the millennium (Fraser et al. 2012), often due to medical advances that have enabled babies who would have previously died, to live. These conditions are more prevalent in areas of higher deprivation and slightly more frequent in males than females (Fraser et al. 2014). A life-limiting condition is one for which there is no reasonable hope of cure and a child will die. A life-threatening condition is one where curative treatment exists, but it sometimes fails. Such conditions include cancer, organ failure, HIV/AIDS, cystic fibrosis, Duchenne muscular dystrophy, cerebral palsy, and

severe neurological disabilities such as brain and spine injuries (Association for Children's Palliative Care 2009). The most common are those with which children are born, but by 16 years old cancer becomes the most prevalent (Fraser et al. 2014). Many of these children are attending mainstream schools.

International and national policies have promoted inclusive education that respects children's rights and encourages the integration of all children, regardless of disability or special educational needs, into mainstream education wherever possible (UNESCO 2009; Department for Education (DfE)/Department of Health 2015). The Children and Families Act (2014) placed a legal duty on English schools to support children with medical conditions and the Department for Education (2015) published guidance on *Supporting Pupils at School with Medical Conditions* a year later.

There is a wealth of literature (Asprey and Nash 2006; Upton and Eisner 2006; Grinyer 2007; Gorin and McAuliffe 2009; Palmer and Leigh 2009; St Leger and Campbell 2008; CLIC Sargent 2012; Helms et al. 2014; Donnan et al. 2015; Paget 2015; Boles et al. 2017) demonstrating the physical (pain, nausea, fatigue), emotional (low self esteem), mental (problems with learning and memory) and social (isolation, bullying, stigma) vulnerabilities of these children. It makes clear how much they and their families need better educational and pastoral support from schools. An international literature review found that the educational support for teachers is very sparse (Robinson and Summers 2012), and Pyle (2013) reported that only 13% of 1580 teachers across maintained schools in England thought that there was sufficient information and resources for teachers to support a child with cancer in school. Robinson and Summers (2012) found no published research about teachers' own views or experiences of working with children with life-limiting or life-threatening conditions.

The aim of the Teaching for Life project was to explore the needs of teachers in relation to working with children with life-limiting or life-threatening conditions. The project was timely because the Department for Education's (2015) guidance for *Supporting Pupils with Medical Conditions* emphasises the importance of good communication between the school, child and family. It suggests

that parents should provide the school with information about the child's medical needs, and recognises that pupils themselves are often best placed to provide information about how their condition affects them. It emphasises the importance of school staff listening and valuing the views of parents and pupils. The policy also states that school leaders need to consult with health and social care professionals, who might train teachers to administer medicines and undertake medical procedures. This is backed up by the English Government's overarching plan to integrate health, social and education services around the needs of the child and family (NHS England/LGA 2016; Department of Health 2016).

Methods

Design and Data Collection

The Teaching for Life project utilised mixed methods and was approved through a university's ethical procedures. Quantitative data was obtained via completion of an on-line semi-structured questionnaire. After piloting, it was sent to 550 teachers within the south east of England who had completed, or were undertaking the National Award for Special Educational Needs Coordination training. Each recipient was asked to forward the questionnaire to any teachers in mainstream schools who they knew had experience of teaching children with life-limiting or life-threatening conditions. The questionnaire asked for information about the teacher's school, their role in the school, their experience of working with children with a life-limiting or life-threatening condition in school, and from where they received relevant education or information. It was accompanied by a participant information sheet which assured them of anonymity.

Qualitative data was obtained through a series of group and individual interviews carried out with teachers. It was recognised that they might find sharing their views and experiences of working with children with life-limiting or life-threatening conditions distressing. Some might have experienced child bereavements. Each interview was recorded and comprised a facilitator and a note taker from the project team, of which at least one had experience of discussing emotionally sensitive issues with others. A protocol for managing distress in the context of an interview was in place. The teachers

were told that they could withdraw at any time and each teacher was provided with a participant information sheet which directed them to charity web sites that offered support should they need it. After each interview, the researchers allowed time in case any participant needed to stay behind to talk.

After an initial piloting of the interview, teachers were grouped into those who had previous experience of working with a child with a life-limiting or life-threatening condition, and those who had not. This captured both the perceptions of the unknown as well as the real experience. The teachers with experience were asked to explain their experiences; describe how these had affected how they taught/teach; share any problems they had encountered when trying to meet the needs of these pupils; describe any current practices, procedures, resources or people who were/are helpful when trying to meet the pupils' needs; and what else would be of help to teachers if it were available. The teachers without experience were invited to describe how they would think and feel if they were informed that that they would be working with a child with a life-limiting or life-threatening condition; what they would do next; what current practices, procedures, resources or people might help them; what in addition would be helpful if it were available; and describe how working with such a child might affect how they taught. After the interview, the interviewer and the note taker wrote a post interview record of key issues, capturing their immediate thoughts about the salient points that had arisen during the interview.

Sample

Ninety teachers, mostly working in mainstream schools, completed questionnaires. Sixty per cent were from the south east of England, the rest from the east and London. Half the respondents (55%) were working as special educational needs coordinators (SENCOs). Thirty eight teachers who were undertaking the National Award for Special Educational Needs Coordination training participated in one of 12 interviews each comprising between one and six participants. Eighteen had no prior experience of working with a child with a life-limiting or life-threatening condition and twenty did. An additional interview with four teachers, a link practitioner and a therapy assistant who all worked

at a Special School was included, as it was felt useful to learn from their extensive experience of this situation.

Data Analysis

The data from the questionnaire was analysed with the help of a computer software package to produce simple descriptive statistics. The interview data comprised audio recordings, notes taken during the interview and the post interview records. These were analysed from an interpretive perspective using thematic coding (Newby 2010; Cohen et al. 2010). The researchers repeatedly read and listened to the conversations to note similarities and differences within the dialogue; to confirm, refute or augment the post interview records and gradually to present sub-themes which were grouped into larger themes. An initial mapping of themes and sub-themes were presented as a spider diagram to the project team who had conducted the interviews, to check their face validity. These were transferred into a fuller text containing quotes within themes. The final stage of analysis comprised further reading and the drawing of connections from within the text and from the questionnaire data, until a clear narrative emerged which the research team agreed fairly and truthfully captured the needs of needs of teachers in relation to working with life-limiting or life-threatening conditions.

Results

The final themes to emerge from the interviews were; the range of life-limiting and life-threatening conditions in schools, current information and support for teachers; teachers dealing with medical, educational and emotional needs; information and support that teachers would like to have. The complete findings, including the descriptive statistics, are described in Durrant et al. (2014). The results presented here focus on the teachers' thoughts and experiences of communicating with parents and children about life-limiting or life-threatening conditions, death and bereavement.

The results from the questionnaire showed that thirty eight (42%) of the teachers were made aware of a child with a life-limiting or life-threatening condition by their parents or carers, seventy five (83%) looked to parents/carers for information about the child's medical needs, and forty two (79%) for

information about the child's non-medical needs. The teachers respected the parents' needs and choices, and looked to parents to guide them.

The teachers with experience of working with a child with a life-limiting or life-threatening condition spoke of how this vital communication with parents was difficult because,

It's the most hideous time for them, but pretending it's not happening or ignoring it is just the worst thing.

Teachers were empathic towards the parents who they recognised were dealing with immense personal emotional trauma, but the teachers with experience of these conversations explained that that parents were often unable to provide what teachers needed.

Some days they could talk about it – some days they couldn't.

... his parents didn't want to really discuss it, because I think the parents were so devastated and angry.

The results from the questionnaire showed that, after the parents/carers, many teachers would look to supplement their understanding from the pupil themselves. This comprised 62% (n=56) of teachers for medical needs, and 70% (n=42) of teachers for non-medical needs. The teachers with experience explained that many pupils don't want to discuss their condition or treatment, and none gave any examples of direct discussions with pupils.

Teachers described themselves being caught between parents and pupils and being fearful about what to say or not to say.

... [teachers] don't know whether you should mention it or whether you shouldn't.

Teachers, who had not experienced working with a child with a life-limiting or life-threatening condition, discussed the potential impact of openly discussing a child's needs at the wrong time,

A lot of parents would like to have had that as a family time or a family way of dealing with it or discussing it. If you're taking that away from them that could open up another area of problems.

Others were aware of the ripple effect to other children and their families.

Are your 'needing to know parents' via a letter, text or email, prior to ... assembly or whatever it's going to be, that your child age 4/5 is going to be privy to information about another child in school potentially dying. That's going to have consequences at home for them, that child's going to go home and ask questions

Teachers with experience shared their own examples of wrestling with the 'should you talk about it?' question. One said,

Difficulty with parents, parents complaining about how we'd dealt with the situation, so obviously this child gets the diagnosis that we're not expecting and then he goes away for treatment and erm children were very upset that he wasn't in school and actually I think the class teacher dealt with it really well. But the parents weren't happy with how it was dealt with, but I think to be honest however it had've been dealt with, there would have been a sector of parents that weren't happy and it was about trying to smooth that over. And because the parents were so agitated it affected the children as well.

Another illustrated one problem when holding a secret for a parent.

... the parents know about the condition, but haven't shared it with him, or shared the prognosis and actually yesterday he'd done some googling himself.

The results from the questionnaire showed that up to two thirds of respondents would hope to turn to health care professionals to supplement their understanding of the medical and non-medical needs of pupils. However the interviews revealed this was difficult due to not knowing exactly who to contact, the professional being unable to answer the specific questions, delays in getting information and difficulties in getting everyone to a multi-disciplinary meeting. They wanted quicker and fuller information but, typically, it was 'hit and miss'. Two thirds of questionnaire respondents (60%) reported that they sought information from the internet.

When the interview turned to discussing a child's death and bereavement, only the teachers without experience of working with children with life-limiting or life-threatening conditions discussed worrying about the general content of lessons. This included whether they could talk about King Henry VIII beheading wives, read stories which might end with a child illness or death and letting slip that there was no cure for a disease.

Most teachers discussed how difficult it was to manage their own personal feelings, while simultaneously maintaining their professional persona as a teacher. One explained how her prior experience affected her current emotions,

I was a bit horrified when I went to one of the schools and they said this child's got ... cystic fibrosis, coz one of my best friends as a teenager died of ... and that actually had a big impact and I now find myself quite panicky about this child.

Most teachers expressed anxiety about how to support others whilst experiencing their own fears and grief.

It's not just his class and his friends, it's also, he's got siblings, so it's them and their friends ... So I think when it does happen it's going to be very, very difficult and it's going to affect the whole school and we haven't got that support. I don't think we're prepared for it, I think it's going to be quite devastating to the staff and probably the children, because it is going to hit them in such a big way in school and also their home environment.

How are we going to, how are we gonna manage that positively and enable the children to grieve? ... If a child in the class were to die, how do you ... I don't think I'd even know where to start with that.

Those teachers with experience of a child bereavement shared their memories of how difficult it had been.

When the first child died quite a while ago there was absolutely no support. I was busking it and felt very vulnerable. The teachers were very upset, the parents very upset, obviously devastated. The other children were very upset and I was making it up as I went along and somehow, sort of got most of it right.

Some spoke of wanting support from others who could come into the school to communicate with the children, but only one teacher cited an example. A counsellor had attended the school, but the teacher said it was not useful. Teachers wanted support for themselves.

It's having that conversation all the time isn't it. Really, really knowing that you can talk to somebody at any point and you have access or not at any point, and feeling confident that you're going to have that dialogue with people.

Teachers with experience, more than those without, were able to go beyond the fear of death and speak empathically about the experience from the children's perspectives.

Some children who are in these situations are just the most amazing people and what can be brought to school, can be brought to the environment, to the children that they're going to be with, [it] is actually really powerful and a real positive. So although it is very stressful and worrying, you've also got to recognise it can be a very positive lesson for all of us!

They shared how they had addressed issues as they arose.

Then he went off and has chemotherapy and obviously that's quite obvious to everybody, with no hair and he sort of ballooned and looked quite different. And I think there were even some bullying incidents where people didn't understand, so that had to be addressed in terms of explaining to other children why he might look like that.

They spoke of empathising with the other children,

The other children in the class found it quite difficult, because obviously it was quite a shock when he came in with his treatment; he had a headscarf and so on. So we had to try to prepare the children. That was the harder thing to sort of say, you know, when he comes back he won't look the same, but you need to treat him the same.

When discussing what can help children, one teacher recalled a teddy bear who was 'wired up' with the same tubes as the child with a condition who was returning to school. The children were able to familiarise themselves with the appearance, ask their questions and understand. When the child returned, he was accepted. Teachers spoke of the importance of having a school culture that embraced all children along with their differences and individual needs.

I think we tried to have high expectations of all the pupils and therefore a pupil with a life-limiting condition wasn't any different to any other pupil.

Another teacher acknowledged the difficulties of sad memories but noted that it can be helpful to remember that children with the same condition are not the same.

These children are different, are being treated, and both are actually in remission. So it's positive, very different outcome to the first child who had with cancer.

Discussion

Teachers communicating about not just medical conditions, but life-limiting or life-threatening conditions, exposed their many anxieties. The Department for Education's (2015) guidance for *Supporting Pupils with Medical Conditions* suggests that teachers should look to parents and pupils for guidance about how best to support the child's needs at school. In this study, many of the teachers had tried this and found that the parents' emotional trauma was so great that they were unable to communicate. Similarly, when they tried to talk to the child, the response was often one of not wanting to talk. Even though, and it is important to state, many children with life-threatening conditions such as cancer, survive, the fear of death was painfully real. Kubler-Ross and Kessler (2014) describe anticipatory grief as being more silent than grief, it is 'not as verbal' due to the preoccupation with the loss that is ahead. Quite simply, as Chadwick (2011) says, grief hurts and death is taboo.

A biopsychosocial model can provide a useful framework for understanding illness and grief (Engel 1977). Biologically, when someone is in a state of high anxiety, stress or shock the brain's amygdala is the first to sense the emotion, the body feels danger and releases adrenaline which prompts the 'fight flight freeze' response. Adrenal glands release cortisol, the 'stress hormone'. The amygdala may stay in overdrive for some time, and cortisol will continue to be produced as long as someone is very stressed. Both inhibit the brain's neocortex, the area of the upper brain that sorts out and

coordinates what to do in a stressful situation, and it is the area that enables people to put words to emotional experiences. Consequently, parents and children have no words.

Psychologically, both parents and children might unconsciously protect themselves from deep emotional pain through unconscious defence mechanisms (Hough 1998). Not speaking could be a form of denial, refusal to believe or admit to a problem; or repression, burying the knowledge or feelings. For younger children, words are not their natural medium of communication, as language development is the task of biopsychosocial development (Robinson 2011). In Papadatou et al.'s (2002) study of 1792 Greek teachers, a quarter avoided class discussions about death after a pupil had died because it was too uncomfortable or because of their own overwhelming emotions. Teachers too are 'lost for words' (Holland, 2003).

Socially, like teachers in other studies (Hinton and Kirk 2015; Dyregrov et al. 2013), the teachers spoke of the difficulties of juggling not only the needs of a child and their family, but those of the class, their parents, the school and sometimes the local community. Some also described that speaking about a child and his/her life-limiting or life-threatening condition at school often felt taboo. They did not know whether to talk about it or not. Teachers were clearly empathic, but worried about how to contain personal emotions whilst fulfilling their professional obligations as teachers. In Spall and Jordan's (1999) study, teachers who worked with children who had suffered loss also struggled to control their emotions and maintain their professional 'non emotional' role as teacher. This role conflict is important because Cullinan (1990) found that teachers' views of their role impacts on how well pupils are supported with grief.

Dixon (2012) pin points the resurgence of greater emotional awareness in the UK to the 1990s, a period which welcomed Goleman's work on emotional intelligence and gave attention to developing social and emotional skills in schools. English schools were encouraged to address the needs of the whole child, not just their learning (HM Government 2004). Dyregrov et al. (2013) suggest that it is the changed social discourse that has led to the expectation that teachers will feel and care and to their

uncertainties about their role, teacher versus carer. Day et al. (2006) and Zemblyas (2003) explain how a teacher's identity is shaped by their school experiences, and the school's culture and their perceptions of their own agency within it. To deviate from the traditional, established culture, one that prioritises learning, leads to feelings of inadequacy and shame. This conflict is surely heightened at a time when the English Government measures school achievement in terms of academic performance (DfE 2017).

Teachers feeling unsupported was a re-occurring theme throughout this research. The Department for Education (2015) encourages schools to have policies in place to clarify roles and responsibilities, and it states that a school's ability to provide effective support to a child with a medical condition relies on good working relationships with health care and other professionals. Like teachers in Norway (Dyregorov et al. 2013), two thirds of English teachers in this study were reluctant to embrace a health care role. They wanted to be able to rely on health care professionals for support, but the interviews showed that they were often unable to get precise and timely information when they needed it and they did not know which health professional to contact. The English Government's plan to better integrate education, health and social services includes a requirement for local authorities to publish a Local Offer comprising local educational, health and social care services (DfE/Department of Health, 2015), but evaluations of the effectiveness of the Local Offer are yet to be published.

In England it is well established that a whole school approach is important for raising standards of pupils' behaviour (Bennett, 2017), setting high expectations for all pupils (DfE/Department of Health, 2015) for promoting pupils' mental health (DfE 2016), preventing bullying (Goldsmiths College, 2011) and for supporting pupils' emotional health and educational attainment (Public Health England 2014; 2015). It means attending to the whole school, the curriculum, pastoral care, the culture and everyone in the school. Children with life limiting or life threatening conditions often develop particular needs related to their physical, mental, social and emotional health which can affect their behaviour and their education. It is argued that a whole school approach, including being an emotionally literate school (Weare 2004), is needed more than ever. Yet this is not mentioned in

Supporting Pupils with Medical Conditions (DfE 2015). It refers to ‘whole-school’ once, in the context of awareness training, and the guidance emphasises inter-professional partnership and the creation of individual school policies to support pupils. Ekins et al. (2017) explain that for policies to be effective, they need to reflect the culture of the school so that the policy can support the whole school’s principles and values. *Supporting Pupils with Medical Conditions* pays much attention to the social and emotional needs of children, but there is no mention of the emotional and social impact for teachers or how they are to be supported.

The gap between the guidance to train staff to administer medicine and care, and the teachers’ comments about the ‘holistic’ reality of educating and caring for very vulnerable children seems to mirror what Rothi et al. concluded from their research into teachers’ experiences of supporting children with mental health problems at school.

Teachers felt disempowered by the current educational climate, often highlighting the link between feeling ineffective and untrained on the one hand and the high demands placed on them by inclusion.” (Rothi et al. 2008 p.1228).

The weight of responsibility for teachers is one reason that the partnership and support from other professionals is so vital for teachers, and why the whole school approach needs to provide a clear and compassionate framework within which to work. The current emphasis on improved child-centred policies and the attention given to children with medical conditions in schools is welcome, but if teachers are to meet the challenges that rising numbers of children with life limiting and life threatening conditions present, addressing teachers’ needs must be part of the plan. There are few detailed resources to support teachers with medical conditions in schools, but a number of UK charities have stepped into the gap to provide good guidance about how to handle child death and bereavement in schools (Coulter et al. 2015; Ekins et al. 2017).

Limitations of the study

The research was based on the views of teachers working in the south and east of England, and these might not reflect the rest of the UK, especially as educational policies and practices vary across the four nations. The sample comprised a convenience sample, many of whom had previous or current connections with one member of the university-based research team. Although not obvious, the possibility of bias, 'wishing to please', could have occurred. Most of the teachers who took part in the interviews were undertaking Special Educational Needs Co-ordination training. This might suggest a group of teachers who had more experience of working with the needs of vulnerable children than teachers in general.

Conclusion

The key drivers for school teachers in England are the promotion of academic achievement through an inclusive approach that supports children with special educational needs and medical needs, and those with both. The Government recognises that a child with medical needs requires the expertise of teachers alongside professionals in health care and social care. The findings from this study suggest that asking teachers to extend their role by relying on obtaining information, skills and training from parents, children and other professionals might be inadequate. Teachers are being asked to perform the very complex role of providing education as well as physical and emotional support to children with life-limiting or life-threatening conditions. The role may continue through death and bereavement. It is a role that impacts on the family, the class, the school and sometimes the wider community. The rise in the numbers of children with life-limiting and life-threatening conditions should be an impetus for increased continuing professional development beyond medical training, it needs to include communicating about illness, death and bereavement. Teachers with relevant experience might be able to contribute practical and emotional support. Policies that seek to be supportive to children with life-limiting and life-threatening conditions need to articulate with a whole school approach that protects and promotes teachers' own wellbeing.

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