A child’s long-term condition will affect the entire family and it is vital that health services offer tailored, family-centred care, say Catherine Lane and Joanne Mason. Siblings of children with life-threatening or life-limiting illnesses can face a number of challenges, yet this is a group that is often unacknowledged as needing specific support. It is essential that the needs of siblings are recognised and addressed as part of a family-centred approach. This article discusses the experiences and challenges faced by siblings in such families and what children’s nurses can do to help. In particular, it outlines a group intervention offered by a community children’s palliative care service.

Abstract

Siblings of children with life-threatening or life-limiting illnesses can face a number of challenges, yet this is a group that is often unacknowledged as needing specific support. It is essential that the needs of siblings are recognised and addressed as part of a family-centred approach. This article discusses the experiences and challenges faced by siblings in such families and what children’s nurses can do to help. In particular, it outlines a group intervention offered by a community children’s palliative care service.

Keywords

Siblings, family-centred care, life-limiting illness, oncology, paediatric nursing, palliative care, psychological interventions

A SERIOUS medical condition in childhood can have an enormous effect on a family system, creating challenges for all family members. There may need to be a reallocation of resources − financial, physical and emotional − and the family schedule may need to be adjusted to fit around the often complex demands of the child’s condition and treatment (Long et al 2013).

This may lead to changes in the structure of, and roles in, the family, and the developmental needs of other children may not be recognised or prioritised. Siblings might be expected to take on some aspects of care of the ill child. A parent might need to give up work to become the main carer, with financial implications. The parental relationship may be put under stress and break down, with subsequent effects on all the children.

Parents in these families are at greater risk of mental health problems, such as stress, anxiety, depression and alcohol misuse (Emerson et al 2006, Laurvick et al 2006), which may make them less available physically and emotionally for their other children and less able to parent effectively (Mulroy et al 2008). Family members can experience tiredness from lack of sleep or care demands, isolation from friends and colleagues, a feeling of being overwhelmed by the situation and frustration at the relentless battles they face in getting their child’s needs met.

The unpredictability of the situation may be difficult for all family members to cope with, given the often complex nature of the disease trajectory. In practical terms, this may mean holidays, outings and social events are often disrupted or impossible to plan. There may also be uncertainty about the child’s prognosis, and the experience of actual or anticipated loss (Menezes 2010).

Potential effects on siblings

Siblings in families with children with a chronic illness may have poor psychosocial outcomes in general (Bellin and Kovacs 2006) and, specifically, emotional problems, behavioural problems, academic difficulties, adjustment issues, peer-related difficulties and low self-esteem (Sharpe and Rossiter 2002, Vermaas et al 2012). Siblings’ social development may also be affected given the difficulty in providing them with ‘normal’ social opportunities.
Siblings might be expected to take on some aspects of care of the ill child and their own needs may not be recognised or prioritised.
However, it is important to acknowledge potential resilience: many families and siblings cope well in difficult situations. Some research suggests that the experience of having a sibling with a life-threatening illness can encourage the development of empathy, compassion, patience and sensitivity (Bellin and Kovacs 2006).

Experiences and feelings
Clinical practice and research (Meyer and Vadasy 2008) identify a number of common feelings and experiences described by siblings of children with life-threatening illnesses, including:
- Guilt, such as feeling they might have caused the illness through something they did wrong, about being the healthy one, or guilt about their feelings towards their sibling or parents.
- Worry, for example about whether they will become ill like their sibling, whether their sibling may die or return to hospital, concern about the family’s financial situation, their parents' emotional wellbeing, or pressure to be the ‘good’, ‘easy’ or ‘able’ child.
- Resentment, such as a sense of unfairness and disappointment about the extra attention and time devoted to their sibling, or the limitations imposed on the family due to their sibling’s illness.
- Sense of loss and isolation, for example feeling different from peers who have healthy siblings, or sad that they cannot have the same type of relationships with their sibling as their peers.
- Embarrassment in relation to their sibling’s differences, appearance or behaviour.
- Responsibility, for example increased independence due to parents’ preoccupation with caring for their sibling, or their own caregiving responsibilities towards their sibling.

All these feelings may create issues in the child’s relationship with their parents and their sibling. However, parents may not be aware of how the sibling is feeling or may be unable to help the child cope with these feelings given their own emotional and practical burden. Research indicates that parents tend to underestimate the difficulties experienced by siblings (Sharpe and Rossiter 2002).

Approaches and interventions
It is important that health professionals acknowledge these issues and attempt to meet the needs of siblings in the families. All assessments and interventions should be family centred, taking into account the needs and strengths of all family members (Burton 2010). The same should be the case in care planning, transition planning and end of life planning. Similarly, support should ideally be offered to the family as a whole and to individual family members, including siblings, as required (Giallo and Gavidia-Payne 2008, Mehta et al 2009).

It is important for information and support to be offered to parents and schools regarding the potential needs of siblings and approaches that can be used to help (Alderfer and Hodges 2010). For example, parents may benefit from support and encouragement to communicate openly with siblings about the illness, treatment and prognosis in a developmentally appropriate way. There is evidence that providing such information helps children identify any misconceptions, provides them with reassurance and helps answer questions they may have which, in turn, enables them to answer questions and help them feel more in control of unpredictable situations (Bellin and Kovacs 2006, Wennick and Huus 2012).

It is important for siblings to have their feelings and experiences, positive and negative, listened to, validated and normalised. Some young people, particularly those experiencing difficulties, may benefit from individual support, such as psychology input in a children’s hospital or community team, referral to child and adolescent mental health services or input within education or social care. There is evidence that taking part in preventive group programmes for siblings can have a positive effect on individuals and families (Meyer and Vadasy 2008, Strohm 2008).

Of course, supporting parents to cope well also benefits siblings, because factors such as good marital relationships, parental mental health and wellbeing, and a cohesive family environment are all protective factors that limit, or protect someone from, some of the potentially negative effects of living with an ill child (O’Haver et al 2010, Gold et al 2011).

Sibling groups
Rationale In addition to the measures described, offering siblings of children with life-limiting illnesses the chance to meet other young people in similar situations, and share their experiences and feelings, can be important in providing reassurance, reducing sense of isolation and normalising feelings (Strohm 2008).

Cognitive behavioural and psycho-educational group interventions are effective in improving self-esteem and family relationships, reducing anxiety, increasing siblings’ knowledge of illness, identifying misconceptions, and improving adjustment, resilience and coping skills (Bellin and Kovacs 2006). Groups can help provide siblings with a sense of being special, valued and thought about. They can also help parents by highlighting potential issues and generally raising their awareness of the needs of siblings.
Groupwork can draw on a number of psychological models such as:

- Cognitive behaviour therapy, which can help the child make links between their thoughts, feelings, behaviour and physiology to help them understand and make sense of their experience and develop appropriate coping strategies.
- Systemic theory, which can help the child think about their situation from different perspectives and how one part of the ‘system’ affects others.
- Stress, self-control or self-efficacy models, which, by helping the young person to develop coping skills, enable them to think that they have more control over the situation, in turn, helping reduce stress (Hamama et al 2008).

In the children’s palliative care service the authors have worked in, groups for siblings have been facilitated for many years by the clinical psychologists and children’s community nurses. The aim of having a joint nursing and psychology service is to consider the physical and psychological wellbeing of the child, and the practical and emotional needs of other individuals in the family, including siblings.

Sibling groups are based on current needs in the service and are usually offered for two age groups: five to ten year olds and 11-16 year olds. They are run over two days in school holidays and incorporate activities adapted to the developmental and emotional needs of the children attending, but broadly fit with the following aims:

- Providing a creative, fun and safe environment.
- Exploring the children’s understanding of bodies, illness and their sibling’s condition.
- Expressing feelings about having a brother or sister with a life-limiting illness, and its implications.
- Identifying and sharing strategies for coping with difficult feelings and situations.

Providing a safe environment Informal, fun activities are used to help children get to know each other and relax. They include active and creative activities, with ground rules set early in the group session.

Exploring understanding Activities such as body drawings, or drawing on parts of the body affected by the sibling’s illness, are used to gauge understanding of the condition and any misconceptions or questions a child may have.

Questions are identified and posted anonymously for a question-and-answer session with a local visiting paediatrician. Examples of questions include: How does Barth syndrome get in the genes? Why do things go wrong in our bodies? Why does my sister get gucky stuff in her lungs?

Preparation and assessing groups

Involving parents and families It is important to involve parents as much as possible in preparing for the sibling group, sharing with them the aims and strategies on which the group is based, and information about the needs of siblings, while being sensitive to the additional strain or burden of guilt this may place on them. Agreement is needed from parents and children about confidentiality and the sharing of information.

Questions are addressed in a manner appropriate to the child’s level of development and understanding and, if appropriate, the child is supported to further explore the question with their parents or health professionals.

Expressing feelings Feelings are expressed and explored through stories, role play, making salt sculptures, producing a collage to depict one’s feelings and other activities. Feelings are normalised and discussion can take place about positive and negative feelings, mixed feelings, and links between feelings and experiences.

Identifying and sharing coping strategies Activities focus on identifying strategies based on thoughts, feelings, behaviour, physiology and support networks. Cognitive strategies may include identifying a ‘special place’ that can be visualised to help the child feel relaxed and happy, or identifying positive thoughts and self-statements, such as ‘I can cope with this’. Use of distraction techniques is also explored. Children explore the effect of stress and difficult feelings on our bodies, and are taught relaxation strategies using controlled breathing, such as by blowing bubbles, and release of tension, such as by squeezing stress balls.

Support networks are discussed, and represented with ‘family portraits’ or ‘helping hand prints’. The former are pictures children draw of family members and other people who support them in different ways: for example someone who cuddles them, talks to them, plays with them, helps them, makes them laugh. The latter involve children making different coloured hand prints and writing on each one the name of someone who helps them in some way.

Children create ‘coping boxes’ or ‘survival backpacks’ in which to keep reminders of the different strategies explored. Each group runs for two days and finishes with a ceremony that involves releasing helium balloons. Siblings identify and write down ‘wishes’ for themselves, their brothers, sisters and families, and attach them to the balloons. Children can attend the group again the next year if they wish.
It is important to provide the groups in the context of an ongoing service, so any issues that arise in a group can be followed up and appropriate support offered. This may include providing information, individual therapeutic work, family work or referral to other services. It could be unhelpful to offer support to siblings without taking a systemic approach and addressing how this can be taken forward in the context of the family (Giallo and Gavidia-Payne 2006).

Evaluation It is challenging to evaluate preventive groups. In the children's community palliative care service discussed here there is a reliance on satisfaction measures and self-reported comments, which have been positive about the group. Siblings report enjoying taking part ('Having fun', 'Making friends', 'Talking to everyone', 'How we all had the same problems') and learning from the group ('I'm not the only one', 'How to cope with an ill brother', 'How parts of the body work', 'Things to do when it's sad', 'Feelings are okay'), and developing coping strategies ('Get out my coping box for feelings', 'Ask someone for help', and 'Let my anger out').

In an evaluation of one of the sibling groups (n=10), all the children thought it was a good idea, all of them reported having fun, 90% stated they had learned about managing difficult feelings and all of them found it helpful to meet children in similar situations. Feedback from parents and health professionals has also been positive. However, further longitudinal studies are needed to show potential long-term benefits of offering this type of support.

Resources Given the powerful nature of sharing experiences with peers, children may gain more from groupwork than from similar input offered individually. When there is a large number of children attending, this is also an efficient use of health professionals’ time. However, this must be considered alongside the amount of staff input required for the group to meet therapeutic needs and the costs of accommodation, materials and time. Many more ideas and resources for setting up sibling groups can be found in Meyer and Vadesy (2008) and on the website of the UK charity Sibs (www.sibs.org.uk), which caters for the needs of siblings of people with disabilities.

Attendance Several formats can be used for sibling groups, such as after school, at weekends or during holidays, and all present different challenges for a service. In the children's community service cited here, the challenges include geography, number of different medical conditions, and practicalities for families in getting siblings to the venue. Sending a child to the group also requires acknowledgement from parents of potential issues for siblings, so it is important to increase parents’ knowledge and awareness of the issues, which may be available, and emphasise the benefits of accessing such provision.

Conclusion The needs of the siblings of children with life-limiting illnesses should not be ignored, and services providing support for families have a responsibility to offer family-centred care that takes their needs into account. Parents might require information about the sibling’s needs and can be encouraged and supported to communicate effectively with their well children and set aside regular time with them that is not focused on their sibling’s illness. Siblings may also benefit from preventive groupwork and individual support, where necessary.

Referenced


