Understanding the spiritual and emotional needs of siblings of chronically sick children with a rare disease

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Abstract

Background

Family morbidity is a concern in the treatment of paediatric patients but guidance and research lacks reference to siblings. Siblings of chronically sick children are at risk of adverse outcomes if needs are not recognized and met. Positive outcomes are possible with appropriate support.

Objective

To identify emotional and spiritual needs of children and young people (CYP) with a sibling with a chronic disease.

Method

A mixed methods study including: validated, UK normed 52-item Kidscreen questionnaire for siblings, proxy version for parents; interviews of each sibling and focus groups drawn from these siblings were recorded, transcribed and subjected to iterative thematic analysis. The setting was Birmingham Children's Hospital NHSFT, UK. Participants were 16 siblings and 16 parents of children with a chronic rare disease aged 8–16, one specialist nurse.

Results

The mean of parents' scores on the questionnaire rated the sibling below the 50th percentile on all ten areas covered. A mean of 34.9 (median 31) for home life shows a significant impact of having a sick child. Siblings consistently rated themselves higher than parents. From the thematic analysis, largely negative consequences of having a sick sibling appeared in all domains. Coping mechanisms were in two main categories: 1. Creative and leisure activities, 2. Family and friends.

Discussion and Conclusion

Having a chronically unwell sibling negatively impacts global wellbeing, and, specifically in this study, their emotional and spiritual development. Further research will be needed to determine if this can be ameliorated

Introduction

Having a family member living with a chronic disease has an impact on the whole family. However, the needs of siblings of chronically sick children is not well covered in literature. Siblings do not feature in

some key guidance to health care professionals. For example, the NICE paediatric end of life care guidelines do not mention siblings.

Our aim was to identify the spiritual and emotional needs of siblings, to see how these might be met. The NHS recognizes the importance of excellence in spiritual care which happens in response to spiritual needs such as meaning and purpose, love and harmonious relationships, need for a source of hope and strength, creativity, trust, ability to express one's personal beliefs and values. NICE in a Local Government Briefing defined emotional wellbeing as including 'being happy and self-confident and not anxious and depressed'. An emotional need is something which detracts from emotional wellbeing and includes issues in relationships with self, others, and the community.

This research project was undertaken by the Centre for Paediatric Spiritual Care (CPSC), part of Birmingham Women's and Children's Hospital NHSFT, UK (BWCH) and commissioned by Inspiring Lives, a charity set up by the family of a young woman who lived with chronic illness.

Method

We identified index patients using the following definition: under 16 with a rare disease or a syndrome without a name which causes a disability, as defined under the UK Equality Act 2010³. We then invited siblings, parents and staff associated with those children to participate while attending Roald Dahl rare diseases events which included siblings. The main exclusion was that the sibling should not themselves have the condition.

This was mixed methods study. Three tools were used: a quantitative questionnaire, interviews and focus groups. The approach to thematic analysis drew on the work of Braun and Clarke. The quantitative questionnaire used was Kidscreen 52 [items] which includes a proxy questionnaire for parents to complete as well as UK norms to compare the data gathered with. It was scored in line with the manual. We registered the project as a collaborative partner of Kidscreen. We used a convenience sample drawing from those siblings who attended Rare Disease Roald Dahl events run by BCH and a sample size advised by ethics committee.

Kidscreen questionnaire

The Kidscreen 52 has been extensively validated, widely adopted, has UK norms and been reviewed in the European context. The instrument is designed to help identify those whose subjective health puts them at risk with the intention of suggesting early intervention.

Table 1
Explanation of Kidscreen 52 domain areas

Physical wellbeing - level of child's physical activity, energy and fitness	Psychological wellbeing– including positive emotions and satisfaction with life
Moods and emotions – how much they experience depressive moods and emotions and stressful feelings	Self-perception – body image, security and satisfaction with self, value to self and how others value
Autonomy – opportunity to create their own social and leisure time, freedom of choice, self-sufficiency and independence	Parent relations and home life – relationship with parents, atmosphere in the home, if treated fairly
Social support and peers – relationship with others and perceived support, acceptance, communication, friendships, part of group	School environment – perception of cognitive capacity, learning, concentration and feelings about school
Social acceptance and bullying – feeling rejected by peers in school and anxiety towards others	Financial resources – whether has enough money to live lifestyle comparative to others

The questions under psychological wellbeing, self-perception, autonomy, home life, peers and social acceptance also had the potential to uncover spiritual needs in relation to our understanding of the term

Interviews and focus groups

In the second stage of the study all siblings underwent a semi-structured interview which was audio-recorded. Parents were available to support the sibling depending on their wishes. The interview questions were based on the topics covered in the questionnaire to aid triangulation. We did one interview schedule for ages 8–11 and another for 11–18 and allocated this based on school year. Seven of the participants accepted an invitation to participate in one of two focus groups along with one staff member. All interviewed were offered the Interviews and focus groups were transcribed by the research team.

Results

Demographics

Sibling and parental perceptions of health-related quality of life

The mean of parents' scores on the Kidscreen questionnaire rates the sibling below the 50th percentile on all ten areas covered. Parents' scores for psychological wellbeing and moods and emotions of the sibling were in the bottom third with medians in the bottom quarter. A mean of 34.9 and median of 31 for home life implies a significant impact of having a sick child. Siblings consistently rated themselves higher than their parents and were more positive about their psychological wellbeing, moods and emotions which, along with self-perception, school and social acceptance were all above the 50th percentile. Siblings

scored Autonomy, Home life and Peers below the 50th centile, which correlated with some of the dominant themes in the interviews.

Key insights from interviews and focus groups

Physical wellbeing: some participants reported medically unexplained symptoms which suggested a somatic manifestation of their situation. Physical and emotional wellbeing was sometimes linked, particularly in relation to sport.

Psychological wellbeing: a small number of participants do not talk to anyone about their feelings. Others have clearly adopted coping mechanisms, for example, sport helping to 'get it all out of my head'.

Moods and emotions: there was clear evidence of siblings feeling resentment and for some abandonment along with sadness, fear, anger and shame with some examples of happiness.

Self-perception: this includes how valued one feels and several siblings talked about the lack of attention they experienced and how parents appeared 'a bit biased' towards the sick child.

Autonomy: the impact of having a sick sibling on what others see as normal life; going to a friend's house or having a party, came across clearly particularly in relation to adopting a carer role.

Home life: the majority of siblings described how home life was negatively impacted through limited time with parents, caring roles, hospital visits and difficult behaviours from the sick sibling which can cause fear.

Peers: There was a clear division between those who found friends a support and others who did not say anything about their sick sibling as they were concerned about bullying, for example '*I'm keeping it quiet because I don't want them to know because they might then start being mean to me and laughing at me that I've got a poorly brother*'. Many mentioned that there was not as much time as they would like to spend with friends.

School: school is perceived positively by the siblings, with some exceptions who find teachers unhelpful and unresponsive to their changing circumstances. Some comments showed how hard it was to get homework done with a demanding schedule at home. However, some clearly found school a safe space and with holidays being challenging with no respite from home.

Social acceptance and bullying: a small number of siblings talked about being bullied but it was not clear if specifically related to having a sick sibling.

Validity and Limitations

Using three methods of data collection aided triangulation and made the study more robust. .

Generalizability are limited by the small sample size but this sample size within qualitative research lies within NRES expectations.

The findings are limited by the age range, which is likely due to using a convenience sample method, but understanding this early adolescent group could be beneficial for early intervention strategies.

Discussion

Emotional and spiritual needs

The spiritual needs that siblings most often referred to were hope, security, creativity, connection, belonging and positive identity. A lack of these needs being met would cause lower scores on the Home Life, Autonomy and Peers areas, as demonstrated by siblings and parents in the Kidscreen-52 questionnaire.

The emotional needs most often talked about were to have fun, lack of anxiety, expressing anger or resentment, fear and sadness.

This research clearly demonstrates a global lack in these needs being recognised or met for children with a sibling with a chronic disease. The hiddenness and isolation of many of the well siblings that came out from this research is concerning.

Impact of having a sick sibling

That the mean of parents' scores on the Kidscreen questionnaire rated the sibling below the 50th percentile on all ten areas suggests a global impact on wellbeing of having a sick sibling, particularly featuring in home life. Well siblings experienced bottled feelings and negative emotions including fear, frustration, resentment and anger emerged in the thematic analysis. Included in this were suppressing grief, a sense of powerlessness and lack of autonomy and control. Some had no confidence in asking for help and support, and there were examples of potential psychosomatic illnesses with few clear other reasons for it.

Fear

Some well siblings spoke of being afraid of something happening to their sibling, and their sick sibling doing something (inadvertently) to hurt them, meaning that home and family relationships may not feel as safe.

Resentment

There was resentment regarding limitations on what the well sibling could do because of the sick sibling's demands or preferences, and parental prioritization of the needs of the sick sibling. One sibling commented that 'I wish I was sick too' in relation to wanting the level of attention that being sick brings. Another commented that they were the least favourite child and another that he does not bother talking to parents anymore as he is not listened to.

Separation Anxiety

A degree of separation anxiety was described, with siblings wondering what is happening and fearing that their sick sibling will die when apart from them, both at school or if the sick sibling was in hospital. This highlights the emotional need of lack of anxiety, as well as the issues of fear and hope that need to be addressed.

Living Bereavement

The well sibling, the sick sibling and the parents are potentially facing multiple or compound losses. Some call this 'living bereavement'. Loss of autonomy at a time when they should perhaps be developing more autonomy is an issue as, for example, they adopt a young carer role. Having a sick sibling can lead to a lack of an independent identity if labelled as x's brother or sister, which is why perhaps some choose not to talk about them. There were existential questions such as 'why our family?' or 'what about me?'. Staff found that siblings sometimes refused to discuss the sick child, possibly being in denial about it.

Identity

There were some examples of positive identity formation; a sense of special treatment – being able to access theme park rides more quickly when with their sibling; a sense of pride from some in being able to care for their sibling and vocation 'I want to be an oncology nurse'; learning about the disease was positive for some. There was also a sense of gratitude for being well.

Discrepancy between parents and children

Siblings consistently rating themselves more positively than their parents in multiple domains suggests that to get a fuller understanding of family dynamics and the impact of having a sick child it is important to talk to both the parents and any siblings.

Coping mechanisms and support

Coping mechanisms were classified into two main areas: Creative and leisure activities; and family and friends.

Providing support that children feel comfortable accessing is vital. Having other significant adults in their lives could be beneficial as demonstrated by the memory making experiences described by the well siblings. This can sometimes be provided by out of school activities including uniformed or faith groups. Providing safe spaces for emotional release or catharsis could be beneficial in allowing siblings to engage with the 'why' question, enable positive identity and self-esteem to grow and self-actualization to be pursued. Fun and memory making is an area siblings can miss out on but this sometimes requires financial or practical resources which are lacking. Encouraging a networked approach to support where this is possible is positive for the well sibling.

Parents were witnessed helping by giving permission to the sibling to articulate how they really felt, and by sharing their own limitations. Parents may need support to process their feelings: feelings of guilt about behaviour towards their children who are not sick came out and may be significant for some.

Conclusion

This research suggests that having a chronically sick sibling impacts global wellbeing, with parents rating the well child below the 50th percentile on all ten areas of Kidscreen 52 questionnaire.

A child's experience of hope, security, creativity, connection, belonging and positive identity and expression of negative emotions are all impacted by having a chronically sick sibling. There is a need to identify siblings most at risk of adverse outcomes and design interventions to mitigate these. Greater awareness of the spiritual and emotional needs of siblings can lead to appropriate interventions being designed and implemented, with the possibility of mitigating some of the negative impacts of their situation. It also highlights the need to be more holistic with the treatment of the sick child and their family by considering the impact on each child in the family. Disparities between parents and siblings' perceptions of need highlights the importance of including children and young people in family assessment.

Future topics for research include which interventions most effectively influence sibling wellbeing and understanding the disparity between parents' and siblings' perceptions of their quality of life.

Declarations

Ethics approval and consent to participate

Ethical approval was gained through the Black Country Research Ethics Committee, project ID 213307.

Informed consent was received from all participants and a parent signed the consent form which included the possibility of publications arising from the research.

Availability of data

The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that there are no competing interests except that Dr Laura Bryson and Dr Susannah Gray are part of the family that set up Inspiring Lives, the funder of this project, and share the experience of the death of a sibling with chronic illness.

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Author's contributions

PN managed the whole project was involved in data analysis and article approval and oversaw the work of SN who was Principal Investigator and wrote the draft of the article. LB contributed to research design, data analysis and final article. SG contributed to data analysis and final article.

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Figures

Figure 1

Demographics

Figure 2