

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. A literature review demonstrated that 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 locating this within a wider understanding of the needs of this population.

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

In the context of the European Union, a rare disease is "one that affects less than 5 in 10,000 of the general population. There are between 6,000 and 8,000 known rare diseases and around five new rare diseases are described in medical literature each week. 1 in 17 people, or almost 6% of the population, will be affected by a rare disease at some point in their lives. This equates to approximately 3.5 million people in the UK. 80% of rare diseases have a genetic component. Often rare diseases are chronic and life-threatening"¹. We chose to investigate siblings of children with a chronic rare disease as, unusually, there were regular events run by the Roald Dahl Foundation at the hospital to which the whole family including siblings were invited thus making our target group accessible in a way which is not the same with other illnesses. Siblings are often a hidden figure in the treatment of a child with a chronic disease which perhaps reflects the lack of research in this area.²

Having a family member living with a chronic disease has an impact on the whole family. However, we found in an initial scoping literature review that the needs of siblings of chronically sick children is not well covered. We searched four different databases: BNI (British Nursing Index), CINHAL (Cumulative

Index of Nursing and Allied Health Literature), Medline and PsycINFO and in addition Google Scholar, EThOS and the Together for Short Lives abstract database. This scoping review was conducted to identify gaps in the literature about the needs of, and support provided to, siblings of children and young people who have a chronic illness. We identified 100 unique relevant articles from the 644 initially found.

Most articles agreed at least that siblings of chronically ill children are an at-risk group, particularly around the time of diagnosis of their sibling's illness, and so require some support to encourage positive outcomes. The support identified varied and included a support group as part of a family intervention (Bergmann 1998, Burke 2003, Evans, Jones and Mansell 2001, Gafoor 2015, Hansford 2013, Phillips 1999, Roberts et al, 2015)³. Other forms of support included books (Ahmann 1997)⁴, involving siblings in patient's treatment (Ferraioli, Hansford and Harris 2012)⁵, a person centred intervention (Nolbris and Ahlström 2014)⁶, young people's suggestions for what they would want in a health communication application (Sin 2013)⁷, weekend therapeutic interventions and leaflets (Ballard 2004)⁸ and a cognitive-psychosocial-respite (Williams, Williams and Katoaka-Yahiro 1997)⁹. The outcomes from such projects included information about their siblings condition(Ahmann 1997, Nolbris and Ahlström 2014, Sin 2013, Williams, Williams and Katoaka-Yahiro 1997)¹⁰; involvement in care of their sibling (Ferraioli, Hansford and Harris 2012)¹¹; less worried (Nolbris and Ahlström 2014)¹²;feeling better (Nolbris and Ahlström 2014)¹³; peer support or feeling that they are not alone (Ahmann 1997, Nolbris and Ahlström 2014, Sin 2013)¹⁴; phsicial improvements (Nolbris and Ahlström 2014)¹⁵;professional support (Sin 2013)¹⁶.

Additionally, 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 siblings¹⁷. This is an omission to note regarding future advocacy for support of siblings.

Our aim was to identify the spiritual and emotional needs of siblings with a chronically sick sibling whose illness impacted day to day life, to see how these might be met. The NHS recognizes the importance of excellence in spiritual care¹⁸ which happens in response to spiritual needs. Research suggests that spiritual needs derive from an understanding of spirituality (Nash 2016, Speck, Higginson, Addinton-Hall 2004)¹⁹ and include constructs 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 values²⁰. Galek et al (2005) from a review of the literature identify seven major constructs that spiritual needs derive from: belonging, meaning, hope, the sacred, morality, beauty, and acceptance of dying²¹. Büsing et al (2010)²² in a study of adults with chronic disease argue that the four key spiritual needs are connection, peace, meaning/purpose and transcendence. Thus it is clear that there is no one universally accepted definition of spiritual need but some common themes emerge such as hope, connectedness, meaning making, engagement with transcendence, and positive relationships.

One approach to identifying emotional needs is that of the Human Givens Institute who argue that there are core needs each person has. They suggest our human needs include, security and safety, giving and receiving attention, emotional intimacy, belonging to a wider community, privacy, status, competence and

achievement, meaning and purpose²³. Related to emotional need is a sense of emotional wellbeing which NICE, in a Local Government Briefing, defined as including 'being happy and self-confident and not anxious and depressed'²⁴. One of the purposes of intervention with the well siblings would be to enhance their emotional wellbeing through meeting spiritual and emotional needs.

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 parents and siblings of a young woman who lived with chronic illness.

Method

We identified 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. This means that the everyday life of the well sibling is likely to be impacted because of the disability, thus patients with rare diseases which do not impact day to day life were excluded. 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 or a different disability.

This was mixed methods study. Three tools were used to aid triangulation: a quantitative questionnaire, interviews, and focus groups. The approach to thematic analysis drew on the work of Braun and Clarke who write specifically about health-related fields²⁵. The authors independently coded the data and then discussed and agreed the themes which emerged. The quantitative questionnaire used was Kidscreen 52 [items], a quality of life health related survey (as the siblings were well) 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 manual²⁶. We registered the project as a collaborative partner of Kidscreen. We used a convenience sample²⁷ (see demographics below) drawing from those siblings who attended Rare Disease Roald Dahl events run by BCH and a sample size advised by the ethics committee which was based on the number of qualitative interviews that would take place.

Kidscreen questionnaire

The Kidscreen 52²⁸ has been appropriately validated, having been tested with 22830 children and their parents across 13 European countries to produce normative data which can be used for comparison²⁹. Kidscreen 52 has widely adopted, has UK norms and been reviewed in the European context and extensively cited³⁰. The instrument is designed to help identify those whose subjective health puts them at risk with the intention of suggesting early intervention. There are two versions of the questionnaire one for 8-11s and the other 12-18s, this is to reflect the different stages of development in these age groups with language and concepts appropriate to the target group. The questionnaire covers eight domains:

| | |
|--|--|
| 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 |

Table 1 Explanation of Kidscreen 52 domain areas

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 as discussed above.

Interviews and focus groups

In the second stage of the study all siblings underwent a face to face semi-structured interview which was audio-recorded with consent. Parents were available to support the sibling depending on the wishes of both the sibling and the parent. The interview questions were based on the topics covered in the questionnaire to aid triangulation and related to all the domains with the exception of financial as this seemed inappropriately intrusive. We did one interview schedule for ages 8-11 and another for 11-18 and allocated this based on school year the sibling was in. Seven of the participants accepted an invitation to be part of one of two focus groups along with one staff member. Interviews and focus groups were transcribed by the research team.

Results

Demographics

Figure 1 Demographics

Sibling and parental perceptions of health-related quality of life

Figure 2 Comparison of Parent and Child Responses in Kidscreen Domains

We analysed the questionnaires as guided by the manual and arrived at scores which enabled us to locate the response in the normed percentile tables that were both age ranged and normed to the UK. 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 percentile, which correlated with some of the dominant themes in the interviews.

Key insights from interviews and focus groups

These are discussed in relation to the domain areas in the questionnaire.

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*'.³²

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 triangulation³³ and made the study more robust. Generalizability is 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. Older adolescents with a chronically sick sibling are a particularly difficult group to access.

Discussion

Emotional and spiritual needs

The spiritual needs that siblings most often referred to, relating to the definitions above, 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 of the questionnaire, as demonstrated by siblings and parents in the Kidscreen-52 results.

The emotional needs most often talked about were to have fun, lack of anxiety, expressing anger or resentment, fear and sadness. Castro et al in their study of siblings of those with chronic diabetes found that well siblings 'display negative emotions such as guilt, anxiety, anger and jealousy'³⁴.

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. Abrams³⁵ argues that the sibling relationship has not been sufficiently explored and may impact the well sibling over their lifetime. Our research is a small contribution to seeking to do this exploration.

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. This is substantiated by other literature, for example, Ballard also found that parents report negative outcomes for the well sibling in a study of children with cancer³⁶. Kathol noted that the well sibling often receives less parental attention and their sense of security can be threatened³⁷. 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 physical reasons for the reported symptoms when these were explored. These difficulties are in line with other research, for example, Alderfer et al in their systematic review of siblings of children with cancer found evidence of negative emotional reactions, a poor quality of life in family, social and emotional domains as well as some difficulties at school³⁸.

Fear

Some well siblings spoke of being afraid of something happening to their sibling, this concurs with Ballard's finding that well siblings of cancer sufferers need reassurance about their sick sibling³⁹. There was also a fear of their sick sibling doing something (inadvertently usually) 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. This is a feature of other literature with Abrams observing that well siblings resent their parents in part because of the lack of attention they receive⁴⁰. 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, which is understood as an unusually strong fear or anxiety to separating from people we have a strong attachment to,⁴¹ was described. This manifested in siblings worrying about 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 excessive level of anxiety, as well as the issues of fear and hope that need to be addressed. Positive psychology perspectives on hope can be helpful here⁴² and may be useful in the future development of interventions.

Living Bereavement

The well sibling, the sick sibling and the parents are potentially facing multiple or compound losses. Some call this 'living bereavement' or 'frozen grief' as the loss is difficult to mourn as the person is not dead.⁴³ 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. Alderfer et al also found some positive outcomes for siblings of children with cancer (which some rare diseases are).⁴⁴

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 as well as support being beneficial for siblings of chronically sick children⁴⁵. 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 spiritual needs such as hope, security, creativity, connection, belonging and positive identity and expression of, sometimes 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.

Consent for publication

All participants agreed to this on the consent form.

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

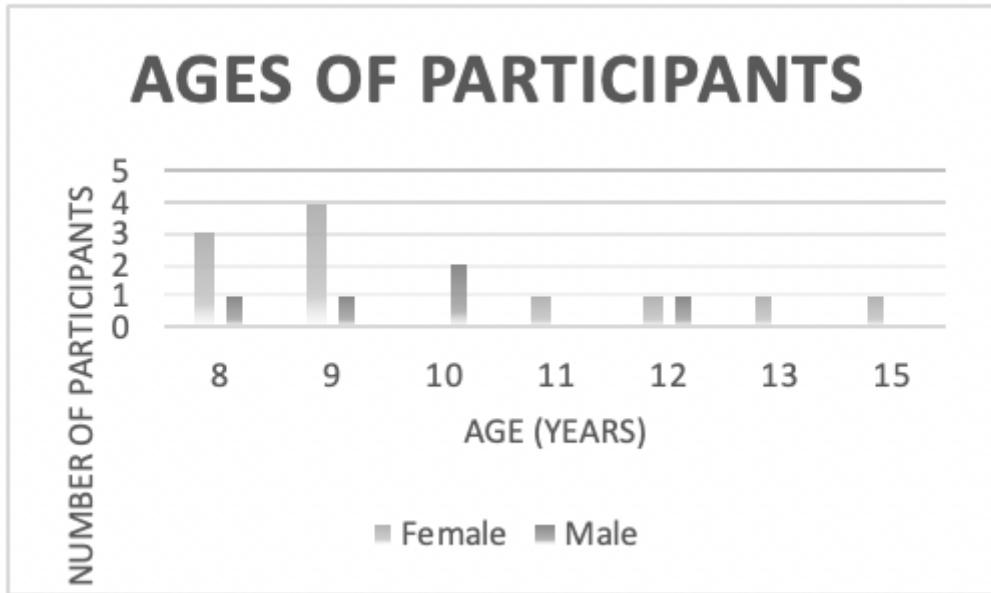


Figure 1

Demographics

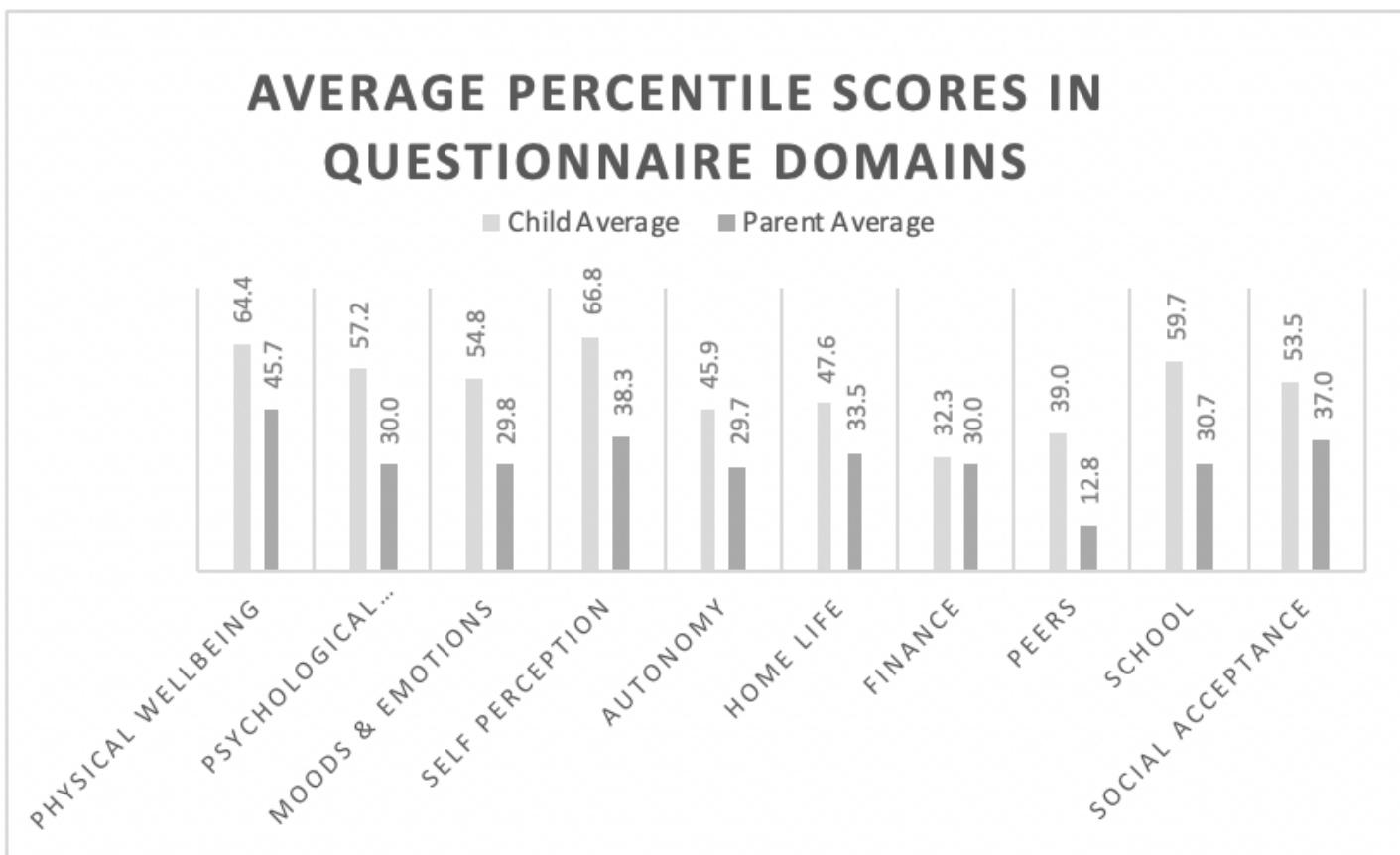


Figure 2

Comparison of Parent and Child Responses in Kidscreen Domains