

THE UNMET NEEDS OF SIBLINGS OF CHILDREN WITH CANCER AND SERIOUS CHRONIC HEALTH CONDITIONS IN AŌTEAROA/NEW ZEALAND

BRIEF SUMMARY

Findings of this study show siblings of children with cancer and serious chronic health conditions in Aotearoa/New Zealand have very high levels of unmet needs. A comparison between the three health conditions found strong similarities in the *types* of unmet needs reported by siblings in all three health conditions, but siblings of children with cancer reported higher *levels* of unmet needs than siblings of children with diabetes and cystic fibrosis. Differences were also found between gender and age group comparisons.

An analysis of international sibling research, including a comparison between the results of this study with an Australian study on siblings of young people with cancer, indicated siblings in Aotearoa/New Zealand may have more problems with negative adjustment and higher levels of unmet needs than siblings studied in international literature.

Findings identified a potential pattern of sibling experiences following a child's diagnosis with cancer or a serious chronic health condition which reflected the existing literature (see Figure 1). While many siblings cope well, there is a group of siblings who experience ongoing psychosocial and adjustment difficulties.

Recommendations arising from this study point to the need for effective, targeted support for siblings with a focus on the following areas:

- age-appropriate information about their sibling's health condition
- guidance on how to support their sibling practically and emotionally
- professional support offered to them close to the time of diagnosis
- support and understanding from peers, family and teachers
- time with parents to feel included and valued
- a safe space where they feel validated and can speak freely
- recreation and 'time out' with other siblings who understand them.

These factors form a strong argument for the development and provision of needs-based support services for siblings nationwide that protect the health and wellbeing of this population.

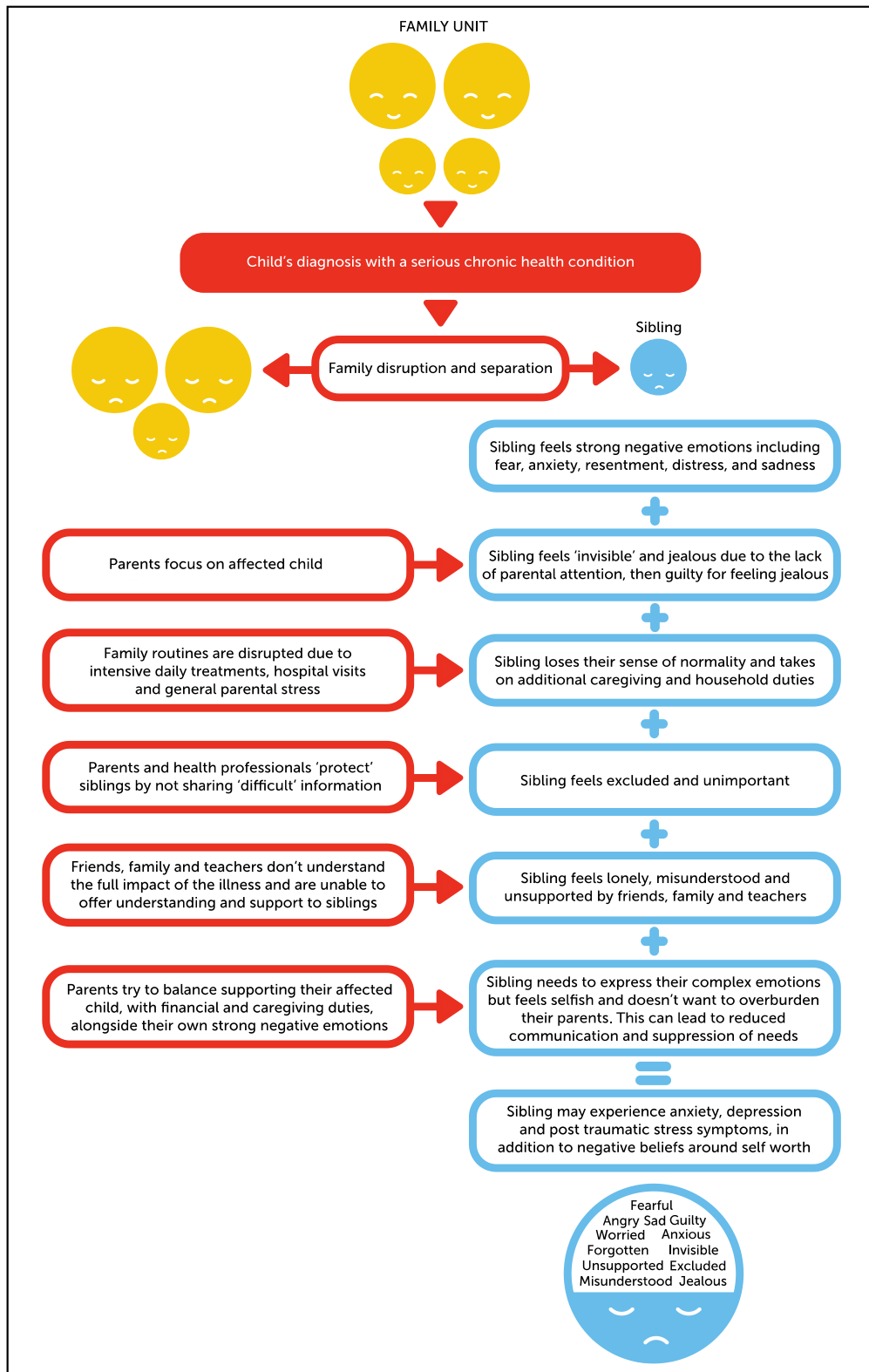


Figure 1. A potential pattern of a sibling's initial responses following a child's diagnosis with a serious chronic health condition.

SUMMARY OF FINDINGS

Thank you again for participating in this Massey University research project aimed at identifying the unmet needs of siblings of children with cancer and serious chronic health conditions. I am extremely grateful to you for taking the time to share your experiences which have been invaluable in identifying and exploring the unmet needs of siblings living in Aōtearoa/New Zealand.

The research

There is evidence to suggest a subset of siblings of children with cancer and serious chronic health conditions have a range of unmet psychosocial needs which have the potential to lead to adjustment difficulties and mental health problems.

As part of this study, a review of targeted, nationwide support services available to siblings in Aōtearoa/New Zealand was undertaken, and found this to be an under-serviced area. With the goal of developing targeted support services that protect and promote the health and wellbeing of siblings, the current research aimed to identify the unmet needs of siblings of children with cancer and serious chronic health conditions.

An online survey was used to identify the unmet needs of siblings of children with cancer, cystic fibrosis, and Type 1 diabetes mellitus. There was a total of 204 respondents across the three health conditions (84 siblings of children with cancer, 47 siblings of children with cystic fibrosis, and 73 siblings of children with diabetes).

Quantitative results

For the data analysis, 'no need' and 'low need' were recorded as 'met' needs, and 'moderate need' and 'high need' were recorded as 'unmet' needs. Overall, results showed the mean percentage of unmet needs for the total sample was very high (57.8%). The average number of unmet needs was 26.01 ($SD = 12.27$, range 0-45). Almost all survey respondents endorsed at least one unmet need (98%), 86.3% of respondents endorsed ten or more unmet needs, and 50% of respondents endorsed thirty two or more unmet needs (out of a possible forty five).

A comparison of the three health conditions showed cancer had the highest average percentage of unmet needs (66.3%), followed by cystic fibrosis (53.0%), then Type 1 diabetes (48.6%). Of the seven domains, INFO (Information about my sibling/whānau member's health condition) and FEEL (Dealing with feelings) had the highest numbers of unmet needs.

Siblings of children with cancer reported significantly higher numbers of unmet needs than siblings of children with cystic fibrosis or diabetes in the following three domains: TO/R (Time out and recreation); PRAC (Practical assistance); and FEEL (Dealing with feelings). The following four domains showed strong similarities between the three health conditions: INFO (Information about my sibling/whānau member’s health condition); UFAM (Understanding from my family); RSIB (Relationship with my ill sibling/whānau member) and SF/OYP (Support from friends and other young people; see Figure 1).

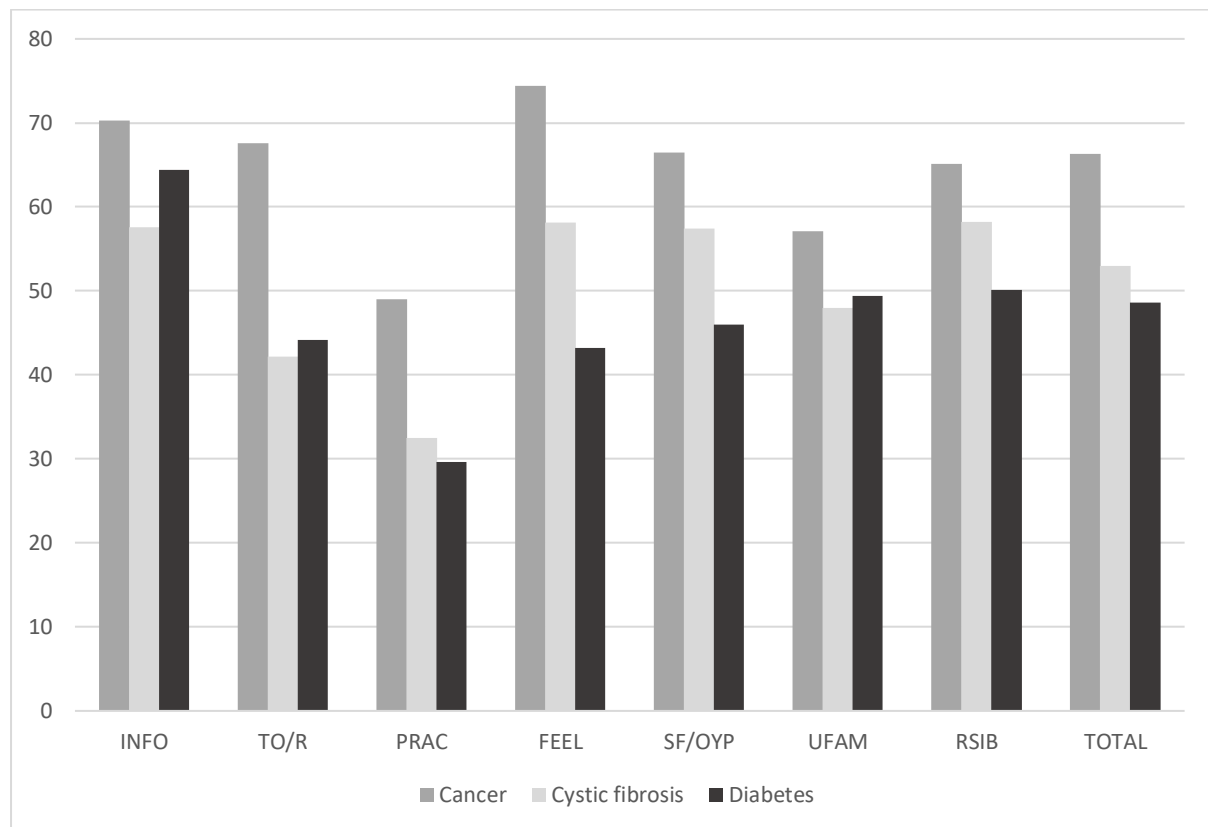


Figure 1. Mean percentage of unmet needs for each health condition

A difference was found between the average number of unmet needs reported by males and females, with females reporting a higher average percentage than males.

A comparison of the average percentage of unmet needs between older siblings (>12 years) and younger siblings (≤12 years) at the time of their brother or sister’s diagnosis, showed the older age group had a higher average percentage of unmet needs than the younger age group.

A comparison of siblings in the ‘cancer’ health condition was done (with an Australian study); this found the domains were strongly correlated but the New Zealand/Aōtearoa sample was consistently higher (approximately 20%). This is noteworthy because it reinforces that sibling’s unmet needs in Aōtearoa/New Zealand are very high.

Qualitative results

The final item in the survey was an open-ended question which aimed to extend the knowledge of the needs of siblings through inviting respondents to reflect on, and express, their own personal experiences. The question was ‘Considering the needs that have been identified, how do you feel your needs would have best been met?’. Responses were collected and the main themes and subthemes were analysed and categorised (see Table 1).

Table 1
Qualitative data: Key themes and subthemes

Theme	Subtheme
Siblings need support	<ul style="list-style-type: none"> • Support from friends, family and school • Support from peers • Support from professionals • Support needs to be offered • Long term support needs
Sibling roles	<ul style="list-style-type: none"> • Being included and given information • Taking care of others
Impact on the whole family	<ul style="list-style-type: none"> • Disruption to the family • Extended family • Financial burden
When things go well	<ul style="list-style-type: none"> • Time, understanding and routines • Individual time

These themes overlapped with the quantitative findings of this study and suggest how siblings needs, if left unmet, can result in psychosocial and adjustment difficulties. Following a child’s diagnosis with a serious chronic health condition, siblings can feel strong negative emotions including fear, anxiety, sadness, resentment and distress. Parental focus on the unwell child can lead siblings to feel ‘invisible’ and ‘forgotten’ due to reduced parental attention. These feelings can lead to jealousy of their affected sibling, then guilt for feeling jealous. This is emphasised when siblings feel ‘left out’ and unimportant when information about their sibling’s health condition is withheld from them by parents and health professionals who are trying to protect them. Siblings may also feel misunderstood and unsupported by friends and family who do not understand the full impact of the diagnosis on them. These complex emotions are often suppressed due to siblings not wanting to overburden their parents, feeling ‘selfish’ for having needs of their own, and feeling guilty for being the ‘healthy’ sibling. Adding to their distress, some siblings report feeling overwhelmed due to changes in family roles and relationships, and disruptions to family life. The impact of these needs (if left unmet) may lead to depression, anxiety, post-traumatic stress symptoms and affect beliefs around self-worth. This is shown visually in Figure 2 below.

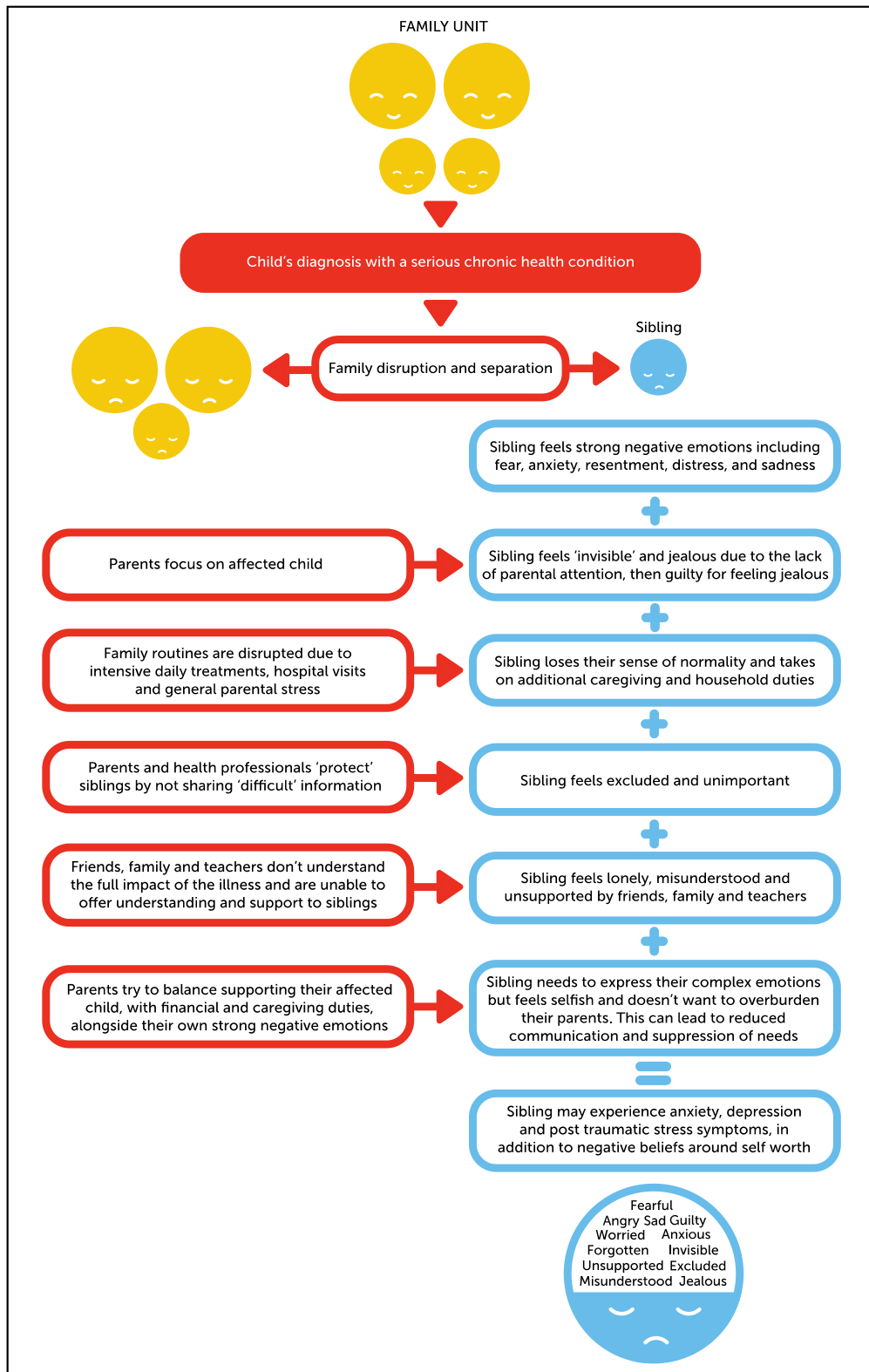


Figure 2. A potential pattern of a sibling's initial responses following a child's diagnosis with a serious chronic health condition.

Conclusion

Findings show there is a common pattern of sibling experiences in the initial phase following a paediatric diagnosis of cancer or a serious chronic health condition. When a sibling's emotional, informational, and relational needs are met in this phase, siblings are likely to adjust to their brother or sister's diagnosis and cope well in the long-term with their changed circumstances. However, if their needs are not met in this initial phase, there is a group of siblings who experience ongoing psychosocial and adjustment difficulties which can cause long-term problems.

It should also be noted that while the focus of the current study was on siblings' descriptions of their unmet needs, siblings also showed remarkable maturity through a willingness to take on care-giving roles, and compassion in their desire to support their affected sibling, and protect their family from any further burden.

In summary, the quantitative analysis detected statistically significant differences in the *levels* of unmet needs of siblings of children with cancer compared to siblings of children with cystic fibrosis and diabetes. However, when we explored these results further with the qualitative results, the *types* of unmet needs between the three health conditions have strong similarities, particularly in the areas of wanting information and support, the importance of sibling relationships, and families understanding and supporting the needs of siblings. These findings support the argument for the development of targeted support services for siblings of children with similar serious chronic health conditions.

Recommendations

Having identified a gap in support services for siblings of children with cancer and serious chronic health conditions in Aotearoa/New Zealand, future research should aim to address this by building on these findings to develop targeted intervention programmes. Because these findings suggest that siblings find it very difficult to request help, due to the complex array of emotions they feel around their sibling's health condition, support services should be offered to siblings so they do not need to ask for help.

Recommendations arising from this study point to the need for effective, targeted support for siblings with a focus on the following areas:

- age-appropriate information about their sibling's health condition
- guidance on how to support their sibling practically and emotionally
- professional support offered to them close to the time of diagnosis
- support and understanding from peers, family and teachers

- time with parents to feel included and valued
- a safe space where they feel validated and can speak freely
- recreation and ‘time out’ with other siblings who understand them.

Further research is required to identify the unmet needs of siblings of children with other serious chronic health conditions, and if the similarities are strong enough, these siblings will also benefit from a targeted intervention programme.

The overarching finding of this research is that siblings in New Zealand/Aōtearoa have very high levels of unmet needs and they need to be offered support. This is reinforced by: siblings themselves, who reported concerning high levels of unmet needs; the response to this research (from siblings, their families, and health workers) which emphasised the need for, and the importance of, better support services for siblings; and the identification of a gap in targeted sibling support services currently available in Aōtearoa/New Zealand. These factors form a strong argument for the development and provision of needs-based support services for siblings nationwide that protect the health and wellbeing of this population.

Future research

I am currently undertaking further research that builds on the findings of the current study with the goal of developing a needs-based intervention programme for siblings.

If you would like to talk to me further about the findings or outcomes of the study, please contact me at siblingneedsresearch@gmail.com.

Thank you again for your valuable contribution to this study.

Ngā mihi nui,



Katie Armstrong