

REVIEW ARTICLE

Communication between parents and well-siblings in the context of living with a child with a life-threatening or life-limiting condition

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Effective parent-child communication may serve to buffer the potential negative impacts of stressful situations on a child. Children who have a brother or sister with a life-threatening or life-limiting medical condition may turn to their parents for help with comprehending the situation, to help maintain their own ability to function across various life areas or to receive emotional support. There is a need for more investigation into the nature and importance of parent-child communication in the context of living with a seriously ill brother or sister. The current paper presents a framework of parent-sibling communication in the context of living with a seriously unwell child, distinguishing the focus of communication (illness-related vs. non-illness-related) and the purpose of communication (information-provision vs. emotional support). Such a framework offers a holistic approach to exploring some of the challenges of communication between parents and well-siblings. The state of current knowledge regarding the focus and purpose of communication between parents and well-siblings is reviewed, and implications for research and possible clinical applications discussed.

Key words: communication; life-limiting condition; life-threatening condition; parent; sibling.

Parent-child communication is widely recognised to have a significant effect on the well-being of children, especially in times of stress.¹ Healthy children who have a brother or sister with a life-threatening condition (where curative treatment may be possible but can fail and may result in death²) or a life-limiting condition (which cannot be cured and will lead to premature death²) live in an environment likely to entail considerable stress.³

Key Points

- 1 Communication between parents and children is a dynamic process, which evolves over time and may be impacted by serious life stressors, such as the serious medical condition of a child.
- 2 It is important to consider the role of information-based and emotion-based communication between parents and well-siblings in the context of living with a seriously unwell child.
- 3 Any consideration of communication between parents and well-siblings should entail a focus on illness-related and non-illness-related communication.

Irrespective of whether the medical condition is newly diagnosed or an ongoing condition, the impact on these well-siblings is likely to be considerable. It is well documented that these environments have the potential to impact on the well-siblings' psychological functioning,^{4,5} social functioning³ and school functioning.⁶ When faced with situations that they find difficult to comprehend, well-siblings commonly turn to their parents for information and emotional support. Not only do well-siblings strive to make sense of their brother's or sister's medical issues, but they also strive to maintain their own functioning across a range of other areas of their life. It is important to acknowledge the challenges and importance of communication between parents and well-siblings across these domains.

The current paper will adopt a particular focus on the communication between parents and well-siblings in families where there is a child with a life-threatening or life-limiting condition. Hence the literature reviewed on parent and well-sibling communication will include both contexts pertaining to a new diagnosis, as well as long-term conditions.

Sub-optimal parent-sibling communication has the potential to have far reaching implications. The ability of parents to maintain effective communication and relations with their offspring when faced with a stressful situation, such as sudden financial hardship, has been found integral to the functioning of their children.⁷ In the context of having a seriously ill brother or sister, the well-sibling is not only impacted directly through their own concerns about their brother or sister, but the impact is likely magnified if they are also faced with reduced parental communication and loss of competent parenting. Although few studies have explored the

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direction of causality, less adequate parent–child communication, when studied in a range of different contexts, has been found to be associated with various adverse functional outcomes, including poorer adolescent self-esteem and mood,^{1,8} greater risk of substance abuse⁹ and poorer academic and school-based competence.¹⁰ For example, inadequate parent–sibling communication, in the context of living with a brother or sister with cancer, has been found to be associated with poorer well-sibling adjustment.¹¹

In light of the far reaching implications of sub-optimal parent–child communication, the aim of the current review was to explore parent–child communication within the context of living with a brother or sister with a life-threatening condition (e.g. leukaemia, neuroblastoma or major organ failure requiring transplantation) or a life-limiting medical condition (e.g. neurodegenerative condition, progressive relapsed malignancy or end stage organ failure). Drawing from a broad range of health contexts, this paper will review what is known about the nature and efficacy of parent and well-sibling communication. This is critical given the complexities and confusion that parents may experience regarding how best to communicate with the well-sibling. Identifying difficult parent–child communication patterns may open-up opportunities for addressing some of the reasons for deficits and developing interventions to guide families towards more effective communication patterns.

The current review will be prefaced by a brief discussion of the development of parent–child communication patterns. It is highlighted that communication between parents and well-siblings should be considered across multiple domains, addressing communication focussed on information provision and the provision of emotional support. Moreover, it is argued that illness-related communication and communication related to other things (e.g. school, friends and hobbies) should be considered, both being of importance to the well-sibling. The current paper proposes a communication framework to explore each of these domains of communication between parents and well-siblings. Where possible, literature will be drawn from the context of chronic paediatric life-threatening or life-limiting conditions. However, where insufficient literature is available in that context, literature will also be drawn from the context of other paediatric disabilities or chronic illnesses, albeit acknowledging how these contexts may differ. The proposed communication framework serves not only to trigger further research, but also to help health professionals guide clinical discussions with families about parent and well-sibling communication patterns and to help identify areas of deficits warranting intervention or support. Potential directions for future research and clinical applications will be considered.

Development of Parent–Child Communication Patterns

Parent–child communication is a dynamic, transactional process, where each individual responds to the cues of the other.¹² Parents may, therefore, establish different patterns of communication with different siblings. Although there is considerable stability in the patterns of interactions between a parent and child over time,^{13,14} the nature and amount of parent–child communication is also known to vary across development, particularly during adolescence.¹⁵ Notably, for girls, parent–child communication has been found to typically decrease in early adolescence, intensifying again in middle adolescence.¹⁵ For boys, disclosure has been found to

decline in early adolescence.¹⁵ However, normative patterns in parent–child interactions may be disrupted when families are faced with a significant stressor, such as the serious illness of a child.

Parent–child communication patterns may be disrupted if the ability of one or both individuals to express information or emotion or to receive information or emotional expressions is compromised. For example, depression, stress, amount of physical proximity and substance abuse may all impact an individual's ability to achieve effective expressive and receptive communication. This is significant given the prevalence of emotional problems among well-siblings⁵ as well as parents^{16,17} living with a child with a serious medical condition. Although a detailed exploration of these issues is beyond the scope of this review, the complex relationship between child and/or parental mental health and parent–child communication has been described elsewhere.¹⁸

Although familial relationships and communication patterns are relatively stable over time,^{13,14} major life stressors, such as a newly diagnosed life-threatening or life-limiting condition or acute and potentially life-threatening crises in a long-standing illness, may challenge long-standing communication patterns. This may result in the emergence of more favourable communication, such as if families feel more united in responding to a difficult situation, or more problematic communication behaviours, such as greater conflict and feelings of being misunderstood. However, there has been little research into familial communication patterns at various time points of the disease trajectory.

Parent and Well-Sibling Communication Framework

To date, the literature on communication between parents and well-siblings within the context of living with a child with a life-threatening or life-limiting medical condition has focussed more on the nature of illness-related information provision.^{19, 20} However, it should be acknowledged that well-siblings value communicating with their parents more broadly across a range of life domains that are important to them,²⁰ which is often neglected in current research on parent–sibling communication. Table 1 presents a framework of parent and well-sibling communication based on the focus and purpose of the communication. Communication between parents and well-siblings may focus on: (i) communicating about the unwell child and illness-related factors and (ii) communicating about other issues that are unrelated to the illness (e.g. school, friends, hobbies, etc.). Both types of communication are likely to be important to the well-sibling. Parent–sibling communication may serve two main purposes, namely: (i) to exchange information and (ii) to provide emotional support. Although the specific content of parent and well-sibling communication may differ depending on whether the communication relates to a new diagnosis or a long-standing life-limiting condition, the concepts espoused in the framework hold relevance for both situations.

Individuals may have differing levels of need for cognitive and affective information to help 'organise' and make sense of their place in the world.²¹ Some individuals may require more information-based communication to make sense of challenging situations, whereas others require more supportive emotional communication. Not only are there likely to be individual differences, but there may be developmental differences in the way individuals seek informational communication and emotional

Table 1 Framework of communication between parents and children who have a brother or sister with a life-threatening or life-limiting condition

	Purpose of communication	
	Information provision	Emotional/Coping support
Focus of parent–sibling communication		
Unwell child and illness factors	<p>(a) Information provision about sick child/ illness</p> <ul style="list-style-type: none"> • Provision of accurate, age-appropriate information about treatments and symptoms • Sensitive to the level of information desired by the well-sibling • Involving the well-sibling in a shared family narrative of the illness experience 	<p>(b) Emotional/Coping support related to illness</p> <ul style="list-style-type: none"> • Emotional support may be verbal or non-verbal (e.g. hugs) • Well-siblings do not always make known their emotional needs to parents • Provision of supportive emotional communication may help well-sibling cope with difficult illness information
Other issues (e.g. school, friends, hobbies, etc.)	<p>(c) Information provision related to other life areas</p> <ul style="list-style-type: none"> • Talking about non-illness-related issues (e.g. school, activities) may help well-siblings maintain some sense of normality 	<p>(d) Emotional/Coping support related to other life areas</p> <ul style="list-style-type: none"> • Well-siblings need emotional support with normal life stressors (e.g. school and friendship issues) • Well-siblings may not wish to bother their parents with these life stressors

communication. To date, the role of individual differences and developmental influences have not been explored in regard to the relative preference of communication types among children with a seriously ill brother or sister and their parents. Each of the four cells of Table 1 depicts various parent and well-sibling communication typologies and will be considered in turn below.

Information provision about the sick child and their medical condition

Illness-related information provision to a well-sibling (cell a in Table 1) has the potential to help the well-sibling better understand and interpret a complex situation that they may have limited, if any, prior experience with. For example, involving well-siblings in activities related to the care of the unwell child, such as in the context of childhood chronic heart disease, has been found to not only facilitate their understanding of the situation but also help create and shape a family narrative of the experience.²² There is evidence that well-siblings commonly have limited understanding about their brother's or sister's illness or chronic medical condition.^{23–25} Parents sometimes perceive that well-siblings have a better understanding of the disease than what is actually the case,²⁶ with the level of information being provided by parents to children often not meeting the well-siblings' desire to know more.^{25,27,28}

Well-siblings who observe changes in their brother's or sister's condition or in their medical interventions benefit from clear, age-appropriate explanations so that they can make sense of the situation. One study found that well-siblings preferred to receive illness-related information from their parents rather than health professionals.²⁴ However, without suitable guidance from health professionals, parents may find this difficult, particularly if there are frequent and rapid changes in the unwell child's condition

and interventions, which the parent is themselves trying to understand and come to terms with.

Parents may feel great uncertainty about how much information to disclose to well-siblings.^{26,29} Open, problem-focussed familial communication patterns have generally been found to be associated with better psychosocial functioning among siblings who have a brother or sister with a disability³⁰ or sickle-cell disease.²⁶ Parents may have complex reasons for not sharing all information with well-siblings, which may include not wanting to distress them, thinking the well-sibling too young to understand,²⁶ not wanting to involve the well-sibling in the medical issues,²⁷ finding it too difficult to discuss the issues with the well-sibling or not understanding the issues well enough themselves.^{26,27} Providing parents with greater support and guidance with respect to well-sibling information provision may help address some of these issues.

Emotional communication and coping support related to sibling's illness

Communication between a parent and well-sibling provides parents with the opportunity to provide emotional and coping support to the well-sibling (as depicted in cell b of Table 1) through their words and non-verbal behaviours (e.g. hugs and other gestures of physical comfort and affection). Receiving difficult or worrying information, without also receiving guidance on how to cope with the situation, may heighten distress. This has been empirically demonstrated in other paediatric contexts, such as receiving information about a forthcoming painful experience, without receiving information about how to cope with it.³¹ Although empirical data is lacking, it is likely that well-siblings may similarly benefit from information about available coping resources when they are faced with worrying information about their brother's or sister's condition.

Parents may find it difficult to provide well-siblings with emotional support as some parents lack insight into the functioning and mental health of well-siblings.³² This may, in part, be due to some well-siblings choosing not to share their feelings with their parents, perhaps not wanting to further burden their parents or feeling that their parents lack emotional availability.^{24,33} Emotional expression has been found to be significantly lower in a sample of children with a sibling with cancer, relative to a control group of children.³⁴ This is problematic in light of evidence suggesting that children who do not express their emotions or seek help tend to have poorer coping outcomes.³⁵

Despite some children not sharing their feelings with parents, a study of 20 families with a child who has a chronic illness found that 67% of the parents held concerns about the emotional health of the well-siblings.³⁶ However, 90% of the parents who had concerns did not access professional resources for emotional support of the well-siblings.³⁶ Some parents may not have known what services or resources were available. Other may have felt that their emotional and physical resources were already stretched as a result of caring for the unwell child, and they may have lacked the time or energy to seek out support for the well-sibling.

Some parents may be aware that they lack the availability and personal resources to communicate effectively with the well-siblings in order to provide them with emotional support. Consequently, they may engage other support systems to try to meet the emotional needs of the well-sibling, such as grandparents, extended family, neighbours, friends, school staff or health professionals.^{24,26,29} Although these supports do not replace the role of the parents, they may help buffer the potentially detrimental impact of parental inability to engage in emotion-focussed communication with the well-sibling.

Exchanging information about other life areas

Sharing information about non-illness-related issues is depicted in cell c of Table 1. Well-siblings commonly report feeling that their brother's or sister's illness dominates their parent's time and attention, and that their own life interests and activities are over-shadowed.³⁷ Following the new diagnosis of a brother or sister with a life-threatening or life-limiting medical condition, well-siblings often describe a loss of normality.³⁸ Similarly, well-siblings who have grown up with a brother or sister who has a life-limiting condition also need the opportunity to exchange information with their parents about issues significant to them. It has been documented in qualitative^{25,37} and quantitative²⁰ studies that well-siblings, across a variety of paediatric health contexts, value the opportunity to communicate with parents regarding other issues that are significant to them, such as school, social activities and friends. It is not known whether the ability to communicate about non-illness aspects of life enhances the connection between parents and well-siblings, thereby improving their capacity to be open about more complex, illness-related topics.

Parents who are faced with the extensive care needs of the sick child may lack the time and resources to communicate with the well-sibling about these other issues. Hence, they may delegate this area of communication to others such as grandparents, family friends or extended family members. Teachers and tutors may also be engaged to discuss schoolwork-related issues with the child.

Emotional/Coping support related to other life areas

Within well-functioning families, parents often have a significant role in helping their child to navigate through the daily stressors of life.³⁹ Through verbal and non-verbal communication, parents can show support and affection, help the child make sense of their experiences and promote healthy socialisation, values and skills.⁴⁰ During adolescence, children may increasingly turn to their peers for this support; however, parents commonly still provide support and encouragement in various ways.²⁶

Children whose families are pre-occupied with issues related to a sick child may find that they have more problems and stressors in other life areas, as things are more easily over-looked. For example, homework might not get completed, well-siblings may forget about class tests, excursion notes might not get returned in time and well-siblings may not be able to attend social activities. However, children who have a very sick brother or sister may choose not to share their own frustrations and worries with their parents, perhaps believing their parents have enough other worries to deal with.²⁴ Parents may, indeed, lack the time and energy to engage with the well-sibling about the challenges they may be facing in other areas.⁵ Longitudinal research is lacking on the potential repercussions that this may have in the long term on parent – well-sibling relationships.

Parent and Well-Sibling Communication Framework: Gaps in the Evidence

Although there is some theoretical and empirical evidence to support the four communication typologies, there are currently numerous gaps in the evidence. There is little available evidence to guide parents with respect to how much illness-related information to provide to well-siblings and how best to provide this information. The broader health literature highlights the importance of developmentally tailored information provision.^{41,42} Much less is known about how other individual difference factors, such as the relative preference for information or emotional communication, may impact on a well-sibling's response to various types of information.

In considering the different parent and well-sibling communication typologies, it is important to acknowledge that little is known about the role of gender differences among siblings or parents. Studies in varied contexts have found that males engage in a greater proportion of information-based communication relative to communication focussed on emotional support, relative to females,^{43,44} with some evidence to suggest that males may find it harder to communicate with the goal of providing emotional support relative to the goal of information provision.⁴⁴ In situations where there is a seriously unwell child, it is commonly reported that mothers spend more time than fathers with the sick child,⁴⁵ which may involve being away from the home during the child's hospital admissions. Consequently, fathers may spend more time with the well-siblings at home. Communication between fathers and well-siblings therefore holds great significance, with well-siblings more likely to turn to their fathers for both informational and emotional needs.

It is well recognised in acute medical contexts that providing children with accurate and age-appropriate information helps

them to lay down accurate memories of an experience,^{46,47} minimising subsequent negatively biased recall.⁴⁷ Well-siblings may think back over events leading up to their brother's or sister's death, however, it is yet to be determined whether different types of parent and well-sibling communication at the time of those events, or shortly after, may impact on the well-sibling's memory of the event, their subsequent emotional response or even their bereavement outcomes.

Directions for Clinical Practice and Future Research

The communication framework outlined in this paper has implications for both clinical practice and future research. The framework provides a useful structure for health professionals embarking on holistic, clinical discussions with families – discussions that address each of the four communication typologies. Moreover, the framework provides the basis for the development of screening tools to identify any areas of particular difficulty in parent–sibling communication.

Although attitudes to disclosure have changed over the last century,⁴⁸ currently health professionals working in Western countries generally encourage relatively open disclosure to family members and children.⁴⁸ Clinically, a fruitful approach may be for health professionals to explore reasons that parents may have for non-disclosure, before advocating that parents adopt a different approach. For example, if parents feel they lack the resources to support the well-sibling if they provided them with potentially distressing information, additional measures may need to be put in place to better support the parent and well-sibling. Once appropriate measures are in place, a possible approach may be for parents to encourage well-siblings to ask questions and to provide information accordingly.

The communication framework outlined in the current paper may be used by multidisciplinary palliative care teams, or other teams providing holistic care for the families of seriously ill children, to guide the development of comprehensive communication interventions addressing a broad range of communication needs between parents and well-siblings. To date, there is a dearth of published interventions designed to facilitate parent-sibling communication in the context of living with child with a life-threatening or life-limiting condition. However, the potential value of parent and well-sibling communication interventions has been demonstrated in other contexts, such as following the death of a brother or sister.⁴⁹

The parent-sibling communication framework may help researchers adopt a more comprehensive research agenda in areas that have hitherto received little attention. For example, research is needed into how well-siblings may differ in their relative need for communication based on information-provision relative to emotional support and whether this may differ according to the child's age and development. Such information may be elicited through interview or the development of a questionnaire assessing the sibling's communication needs and preferences regarding the focus and purpose of parent-sibling communication. Consideration is also needed into whether individual difference factors may be associated with well-siblings desiring relatively more illness-related communication or more emotion-focussed communication from their parent. More research is needed to explore potential gender differences among parents

and in well-siblings with regard to their preferences and comfort with the various communication typologies.

Longitudinal research is needed to investigate whether deficits in some areas of communication between parents and well-siblings have long-term impacts on well-sibling functioning or the parent-sibling relationship. Longitudinal research may also shed light on any potential differences in familial communication patterns at various stages of illness chronicity. Moreover, it may be valuable to contrast parent and well-sibling communication patterns in acute versus chronic medical situations.

Finally, it would be fruitful to consider whether certain patterns of communication between parents and well-siblings during the illness of the sick child are associated with more favourable subsequent well-sibling adjustment (including bereavement outcomes). For example, research is needed to determine whether the provision of illness-related information is most effective if coupled with coping or emotion-focussed communication. One may hypothesise that neither type of communication is as effective as both combined.

Conclusion

The current paper has outlined a communication framework to describe communication typologies between parents and well-siblings in the context of living with another child with a life-threatening or life-limiting condition. The framework highlights the importance of both illness-focussed and non-illness-related communication, giving consideration to communication with the purpose of either information-provision or emotional support. This framework serves to provide a more holistic framework for considering communication in this context, serving to guide clinical practice and target specific areas for further research.

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