

# Parenting interventions for childhood chronic illness: A review and recommendations for intervention design and delivery

Journal of Child Health Care  
2015, Vol. 19(1) 5–17  
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sagepub.co.uk/journalsPermissions.nav  
DOI: 10.1177/1367493513496664  
chc.sagepub.com



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## Abstract

Every day, thousands of children suffer the effects of chronic health conditions and families struggle with illness management and children's behavioural and emotional adjustment. Many parents experience difficulties with their caregiving role and lack confidence in their ability to manage their child's illness and ensure the child's well-being. While there is consistent evidence as to the extent and impact of childhood chronic illness, there is a paucity of evidence-based parenting approaches to help children with chronic health conditions and their families. This paper provides a narrative review of the current literature to examine relationships between chronic childhood illness, emotional and behavioural disorders and parenting. Key guidelines and recommendations for the development of evidence-based parenting programs for parents of children affected by chronic health conditions are provided.

## Keywords

Child health, childhood illness, chronic illness, parenting

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## **Introduction**

Childhood chronic illnesses threaten the health and development of children and well-being of families worldwide, placing an enormous burden on affected individuals, their families and the broader community. This paper provides an overview of the way parenting interventions have developed over the past two decades and provides recommendations for research and development of future strategies to assist parents of children with chronic illness. An electronic database search for articles from 1990 to 2012 using PsycINFO®, Cinahl via Ebsco and Medline via OvidSP was conducted using the keywords child behaviour, chronic illness, child abuse, abuse and neglect, parenting support, parenting interventions, parenting program, atopic, eczema, asthma, health behaviour, parenting, child psychology, chronic disease management and dermatitis. Names of key researchers in the field and the 'related articles' function were then used to increase the output by four articles from 1982 to 1989. In sum, the search strategy yielded a number of articles from which the reference lists were scanned for missing studies yielding one more article from 1982.

Childhood chronic illnesses are common and prevalence rates are on the rise (e.g. Asher et al., 2006; Craig et al., 2007). Chronic and long-term conditions, that is, ongoing impairment characterised by a physical condition causing the use of health services beyond routine care, account for a considerable proportion of disease burden (AIHW, 2010, 2011). The impact on children and families depends on severity and the nature of the condition. For example, asthma may be relatively easy to manage and is rarely fatal, unlike childhood cancer that may result in death and usually requires intense, hospital-based treatments (AIHW, 2010). However, the leading cause of disease burden in Australian children is asthma possibly due to its high prevalence, and although uncommon in children, both Type 1 diabetes and cancer are identified as areas for concern (AIHW, 2010, 2011): diabetes because its prevalence is on the rise and cancer because with increasing survival, the burden of long-term treatment and disease increases.

Psychological morbidity and poor quality of life outcomes have been well documented (e.g. Svavarsdottir and Arlygsdattir, 2006; Pinquart and Teubert, 2012). The effects of childhood chronic illness on the family appear similar across culture and include a sense of loss of normal family life, uncertainty about the future, isolation, family conflict and effects on siblings (Fawcett et al., 2005; Vermaes et al., 2012). Additionally, there is a considerable amount of research examining the burden of caring for a child with a chronic illness (e.g. Dewey and Crawford, 2007; Holm et al., 2008).

Despite consistent evidence as to the extent and impact of childhood chronic illness, existing psychosocial approaches to help children and their families have been inadequate and have had limited success. This paper offers a narrative review to draw together relevant current literature to outline the links between chronic childhood illness, emotional and behavioural disorders and parenting, briefly overview the current approaches to intervention in order to provide recommendations for the development and testing of evidence-based parenting programs for carers of children affected by chronic health conditions. The focus of this review is on preadolescent children, as different developmental issues arise as children transit into adolescence and self-management of their condition becomes increasingly important.

### ***Impact of chronic conditions on children***

Childhood illness has an impact on children in a number of ways, including their broader health, daily routines, behaviour and emotional adjustment. Children with chronic illness are more likely

to experience problems with their emotional or behavioural adjustment compared to children without a chronic illness (Blackman et al., 2011; Hysing et al., 2007, 2009) and these problems appear to have increased over time (Blackman and Conaway, 2012). Problems include elevated rates of internalising problems such as depression and anxiety as well as externalising problems such as aggression (Pinquart and Shen, 2011), lower self-esteem (Sultana et al., 2007), social difficulties (Meijer et al., 2000) and using the illness as a way of getting their own way or avoiding school (Eksi et al., 1995).

There is limited evidence that specific childhood illnesses are linked to particular risk factors for behavioural and emotional problems (e.g. Stein and Jessop, 1982). While it has been suggested that the co-morbidity between childhood illness and behavioural and emotional problems could be due, in part, to a genetic predisposition (Wamboldt et al., 1998, 2000); it is not clear whether this is due to shared genetic and environmental risk or phenotypic causality, that is, due to genetic susceptibility or one disorder influencing risk of the other. Chronically ill children may experience higher levels of adjustment problems for a number of reasons, including the physical limitations associated with the illness, requirements linked with adherence to medical regimens, school absenteeism as a result of the illness, altered or limited opportunities for socialisation and feelings of helplessness, increased dependency and self-consciousness as well as worries about the illness (Bennett, 1994; Eiser and Berrenberg, 1995).

There is also growing concern that a range of chronic health conditions place children at higher risk of child physical abuse (Svensson et al., 2010) and neglect (Jaudes and Diamond, 2011). A recent Swedish survey of 2510 children aged 10, 12 and 15 years found that children with chronic disease/disorders and/or long-term disabilities were at increased risk of child physical abuse (Svensson et al., 2010). At the same time, a retrospective chart review of all children documented to have been abused or neglected between 1977 and 1984 found that chronic illness had placed children at higher risk of neglect during that time period (Jaudes and Diamond, 2011). Considering the susceptibility of children with chronic illnesses to behavioural and mental health conditions and the finding that emotional and behavioural problems place children at even higher risk of child abuse and neglect raises concern for the vulnerability of children with chronic illnesses.

### *A cross-condition approach*

Most childhood illnesses fall under a specific medical discipline such as gastroenterology, endocrinology or dermatology. Health services are thus organised around specific conditions, and as a result, much of the research focuses on illness-specific characteristics. However, numerous researchers have found that diagnostic category per se does not predict adjustment, but rather factors such as the family environment, illness severity and chronicity play a more important role (Bennett, 1994; e.g. Stein and Jessop, 1989; Svavarsdottir and Arlygsdattir, 2006).

Morison et al. (2003) propose that models of service provision to chronically ill children need to focus on generalised illness aspects. This is consistent with research that has found that there is often more variability in adjustment within diagnostic groupings (Bennett, 1994; e.g. Stein and Jessop, 1989; Svavarsdottir and Arlygsdattir, 2006) and that local communities are more likely to have children with a range of conditions but only a small number within each illness category. Furthermore, the authors argue that the most effective intervention strategies for families view psychological adjustment as a function of common dimensions around which illnesses vary, rather than as a function of specific illnesses.

### *The importance of parents, carers and families*

There is increasing evidence for the importance of social environments in determining health outcomes (Svensson et al., 2010). For children, parenting plays an integral role, where parenting practises and the broader family environment (e.g. modelling and encouragement of healthy lifestyle behaviours such as diet, exercise, taking of medication and compliance with other aspects of a clinical care plan and personal stress and family conflict) may contribute to the course of childhood illnesses. Overall, the literature suggests that the adaption to illness following diagnosis seems to be related to individual and family characteristics rather than to illness characteristics (Frank et al., 1998b) and that the family environment is the most important factor related to children's adjustment (Perrin et al., 1993).

Primary responsibility for disease management in children usually rests with the parent and can include medication, therapeutic interventions (e.g. physical therapy) and services, specialised diets, avoidance of health risk behaviours and situations and hospitalisation (Barlow et al., 1998). Carers of chronically ill children need to successfully integrate parenting behaviour related both to general behaviour and also those specific to illness management. Chronic illness management requires the parent to observe the child's behaviour and closely monitor daily activities, administer medication and other medical interventions, respond quickly and effectively to medical emergencies and use problem-solving skills to ensure appropriate care is given. At the same time, parents need to balance this with providing the child with educational opportunities as well as developmentally appropriate play and social experiences (Sullivan-Bolyai et al., 2003). Furthermore, these tasks need to be integrated within the broader family context, which may involve caring for other children, as well as work and other demands.

There are two potential pathways for the family environment to impact child health outcomes and emotional and behavioural adjustment. The first is through the direct influence of ineffective parenting practices and the second is through the impact of family stress on the child's emotional states and their psychobiological regulation (Klennert et al., 2008). In particular, parental distress and global adjustment (e.g. anxiety, depression and stress) are consistent predictors of child adjustment (e.g. Frank et al., 1998a). These effects are often mediated via the impact of parental adjustment on parenting practices such as a reduced monitoring (Eckshtain et al., 2010), disruptions to routines (Peterson-Sweeney et al., 2010) and negative and critical parenting (Fiese et al., 2008).

Consistent with the general parenting literature, authoritative parenting practices have been associated with better illness control and regimen adherence as well as with better child adjustment (e.g. Botello-Harbaum et al., 2008; Park and Walton-Moss, 2012). In contrast, the use of ineffective parental problem-solving strategies (e.g. Wade et al., 2000), overprotective parenting (e.g. Gustafsson et al., 2002), parental criticism and rejection (e.g. Wamboldt et al., 1995) and lower parenting self-efficacy (e.g. Streisand et al., 2005) as well as higher parenting stress (Helgeson et al., 2012) have been associated with higher morbidity and more emotional and behavioural problems. Parents of chronically ill children have different expectations for behaviour and may discipline the child less often based on different attributions for the child's behaviour (e.g. Ievers et al., 1994). Parents may perceive their chronically ill child as more vulnerable, and this impacts on their parenting and illness management (Anthony et al., 2003; Mullins et al., 2007).

Higher family conflict especially that related to the illness has also been associated with poorer disease outcomes and child behaviour and emotional problems (e.g. Lewin et al., 2006). Conflict may reflect differences between parents in expectations and parenting behaviours relating to

managing their child and the illness (Eiser et al., 1991); and for older children, ineffective parent-child communication (Wysocki et al., 1999). Furthermore, carers may have very different views and perspectives about the child's illness, behaviour and support needs.

### *Parents' causal explanations and potential for change*

Parents may have a range of beliefs and hear a range of explanations, which influence their decisions on how to manage their child's behaviour, and their beliefs about the amount of control that they can have. For example, parents attribute behavioural difficulties in children with asthma to inhaled corticosteroids (Morawska et al., 2008), which may impact on both willingness to adhere to medication and on how to manage the child's behaviour. Parents who tend towards a negative self-attributional style view their child as more vulnerable, and thus may respond with over-protective parenting behaviours (Carpentier et al., 2008). Such expectancies can contribute to beliefs and attributions that can maintain cyclical, reciprocal interactions between parental practices and child emotional and behavioural difficulties.

The illness representations model (Leventhal et al., 2008) suggests a number of avenues for understanding the ways that illness can be perceived, which will in turn affect the way that the parent is likely to understand, and thus cope with their child's health difficulties. These ways of representing the child's illness and any changes in emotional or behavioural adjustment are likely in turn to have a profound influence on the way that the parent understands and responds to their child's behaviour and development. Parental self-efficacy beliefs about their capacity to change habits and effect change are likely to be central to promoting health, within social cognitive theory (Bandura, 2004).

### *Psychosocial interventions*

Carers of chronically ill children report significant needs for information and often rate existing information sharing as inadequate (Barlow et al., 1998; Hummelinck and Pollock, 2006; Tong et al., 2010). Meta-analytic data across interventions designed to improve adherence with medical management across childhood chronic illness show moderate effect sizes, and combinations of behavioural and educational interventions show the highest effect sizes; however, there is significant variability between studies in outcomes (Graves et al., 2010). Although the focus of most interventions has been on knowledge (Clarke and Calam, 2012), behavioural interventions are more effective than educational interventions in affecting health-related outcomes in paediatric chronic illness (Cushing and Steele, 2010). Most research has focused on enhancing medical adherence and health outcomes, with few studies considering behavioural and emotional outcomes, which appear to be linked to illness morbidity.

There are limited data on parenting interventions for chronically ill children (Kirk et al., 2012), with the exception of single-case studies (Bagner et al., 2004), educational interventions (Seid et al., 2010; Warschburger et al., 2003) and studies focusing on a single disorder (Applegate et al., 2003; Monaghan et al., 2011). One randomised clinical trial assessing the effectiveness of brief behavioural management for reducing child distress during parent-administered needle procedures found no significant intervention effects (Slifer et al., 2009). Existing parenting intervention approaches to improve adherence and to support families have lacked an explicit theoretical framework and have largely focused on education and social support and outcomes have been mixed (Butz et al., 2005; Gibson et al., 2002; Nolan et al., 1987). Finally, while mothers and fathers

may have quite different experiences in relation to caring for their chronically ill child, very little is known about varying service and support needs of different carers.

### ***Parenting interventions***

Given the importance of parenting and family factors and the emerging evidence for psychosocial interventions in childhood chronic illness, combined with calls for more comprehensive services that meet identified parenting needs, we suggest that parenting programs may be an important element of the management of chronic childhood illness in preadolescent children. The outcomes of parenting programs for childhood chronic illness should focus on enhancing positive parenting skills, parent illness management skills and reducing family stress, with the aim of improving child outcomes including child behavioural and emotional adjustment, quality of life and ultimately better medical adherence and better child health.

Behavioural parenting programs are the most empirically supported intervention for preventing and treating child behavioural problems (Lundahl et al., 2006). Such programs focus on the impact of parenting on the onset and maintenance of behavioural problems and are based on social learning models of parent-child interaction and also identify learning processes that contribute to the development and maintenance of coercive parent-child interactions (Patterson et al., 1992). They have demonstrated significant reductions in early child behavioural problems (Brestan and Eyberg, 1998; e.g. Sanders et al., 2000), with these effects maintained over time (e.g. Hood and Eyberg, 2003; Sanders et al., 2007). Programs have also been effective in improving a number of parental outcomes including reducing dysfunctional parenting styles, increasing parental self-efficacy, and decreasing parental stress (Nowak and Heinrichs, 2008).

Meta-analysis has identified the key elements of effective parenting programmes (Kaminski et al., 2008), including increasing positive interaction between parent and child, developing skills in communicating about emotions, increasing consistency in parenting and more effective use of time out. Parenting interventions have the potential to increase positive parenting practices associated with improved child outcomes and empower parents to develop better daily routines and to encourage their children to carry out health-related activities that they might otherwise resist. By reducing parents' use of ineffective, coercive and inconsistent strategies and increasing use of positive, effective and predictable strategies, parenting interventions can lead to fewer child behavioural problems and better child adjustment. Furthermore, if parents are more effective in managing their child's illness through a more consistent approach, focused on routine and skill building, the quality of life for the child and family is likely to improve and the parents should experience less stress. Thus, by targeting parenting, interventions have the potential to impact both on the direct and indirect pathways leading to child behavioural and emotional problems.

Based on the relationship between behavioural and emotional problems and childhood chronic illness experience, what is understood about processes contributing to these problems (Patterson, 1982), current evidence for behavioural parenting intervention (Kaminski et al., 2008; Lundahl et al., 2006) and effective approaches to illness management (e.g. Ellis et al., 2008; Kratz et al., 2009), we propose a parenting intervention for parents of chronically ill children should feature: (1) a brief psychoeducation component, with a focus on the nature of the specific illness, its causes and best practice in illness management, to address the need for adequate information identified by parents of chronically ill children (Barlow et al., 1998; Hummelinck and Pollock, 2006; Tong et al., 2010); (2) strategies for effective illness management, such as building good treatment routines, to ensure parents are best equipped to maintain medical adherence; (3) information to assist parents to

understand the link between childhood illness and behavioural and emotional adjustment, to emphasise the importance of good illness management and link to effective use of parenting strategies; (4) strategies to assist parents in preventing and managing their child's anxiety and (5) strategies to prevent and manage child behavioural problems.

In designing and implementing such a parenting intervention, a number of factors would need to be considered. First, it is essential that the intervention is delivered in conjunction with appropriate medical management of the illness and does not substitute for or contradict best practice illness management. Ideally, the intervention would be delivered in the context of the child's existing treatment, for example, by conducting the program through specialist clinics or in hospital settings. Second, the burden of intervention for families needs to be given serious consideration as many families are already taking part in intensive intervention, have considerable time pressures and are under significant stress. Thus, interventions should be as brief as possible and delivered in a cost-effective manner (e.g. Morawska et al., 2011). Third, in order to ensure that the intervention is viable and sustainable, it needs to be effective for families of children with a variety of chronic illnesses, rather than focusing on a single diagnostic category. However, consideration of how illness-specific information would be communicated to parents needs to be incorporated in program design and delivery. Finally, as health provision and organisation of services differs substantially between services, countries and regions, and interventions need to be sufficiently flexible to be delivered to families with varying characteristics and in different circumstances, the issue of who and under what circumstances such programs should be delivered needs to be considered. It is likely that this would best be decided at the individual service level, taking into account different service needs, funding and practitioner perspectives; however, a number of options are possible. For example, a member of the child's medical team (e.g. nurse educator) might deliver the program or a service could employ a consultant (e.g. psychologist) to deliver such interventions to their client group on a regular basis.

### *Recommendations and future research*

A number of areas of research in the context of childhood chronic illness warrant further attention. While the relationships between child health outcomes and parenting and the family environment have become increasingly well established, the mechanisms explaining these relationships are less clear. Drawing from the general parenting and the health behaviour literature, a number of models can be applied; however, these have not been explicitly tested within a childhood chronic illness context. For example, while Patterson's (1982) coercive process model may be extended to illness management parenting tasks, further examination of this relationship would assist in developing specific, targeted interventions and strategies to assist parents. Observational studies exploring the dyadic interactions within the illness management situation could help to elucidate the pathways of coercion and withdrawal that contribute to non-adherence to medical advice. Similarly, studies should investigate the relationship between chronic health conditions and the experience of child abuse and neglect, including the parenting behaviours and attributions, which are particular to this parenting context, with the aim of developing interventions to help parents cope more effectively and be better equipped to parent effectively and non-coercively. Finally, a consumer-focused perspective, investigating both parent and child views on the illness management experience, can enhance our understanding of the interaction between parenting and childhood chronic illness and assist in establishing interventions that explicitly encompass a consumer voice (Sanders and Kirby, 2012).

Application of the illness representations model (Leventhal et al., 2008) would suggest that parents will have representations about the illness, including its controllability, and hence an implicit set of expectations about these. In addition, parents will similarly have beliefs about any behavioural and emotional difficulties that accompany their child's physical health presentations. Furthermore, Morrissey-Kane and Prinz (1999) identified the importance of external, stable attributions in determining the extent to which parents believed they were able to change behaviour. Research identifying these representations and attributional biases and helping parents to reframe these to see that both behavioural and emotional adjustments and parental self-efficacy in managing these are dynamic rather than fixed might help reduce distress for both the child and the parent.

Given that the literature is moving towards consensus on the active elements of parenting programs (Kaminski et al., 2008), and an evidence base for a range of modes of delivery has already been developed (Sanders, 2012), research would be helpful in determining the best ways of offering and delivering these to parents of children with long-term illnesses. Such research and development of interventions should be embedded within a consumer-focused process (Sanders and Kirby, 2012), which takes into account the perspectives of both parents and practitioners, and empowers collaborative partnerships between researchers, practitioners, parents and children in designing the best service delivery approach. We do not know, for example, whether parents will see a need for some sort of parenting assistance. Perceived need is, of course, a first step towards engagement. With very limited time, parents will be making an active choice on how they will allocate their personal resources. Furthermore, the extent to which explanations need to be disease-specific in order to most effectively engage parents is unknown. It is an empirical question whether the intervention itself needs to be named as targeting a specific condition or whether more generic approaches to parenting sick children will be engaging and effective. The literature on parenting already shows key elements of positive interaction and communication that help to alleviate a very wide range of difficulties. Many illnesses carry common difficulties in relation to managing uncomfortable, painful, restrictive and time-consuming procedures, and in many cases, the basic approach of anticipation of difficulties, preparation and problem-solving will be the same. Are parents, however, better able to engage with information if there is a disease-specific 'wrapper', or are they happy to engage with more generic approaches if they know that there is a strong evidence base? Is it sufficient for a key professional or other adviser to provide testimonial that a parenting intervention is likely to help their family, or do parents want to know that the programme that they are being offered is specific to, for example, asthma, or diabetes or heart disease? Addressing these issues is key to provision of a system that can have broad reach and be widely disseminated across the extensive range of possible physical conditions, to improve child health as well as parent and family well-being.

The final element to examine in future research focuses on issues of implementation in existing service delivery contexts. Health services across the world have very different organisational systems, priorities, ways of delivering services and funding structures, which impact on ways that evidence-based interventions would be delivered to parents. Interventions could be embedded and integrated within existing multidisciplinary teams or could be referred to children's primary care physicians or other care systems or outsourced to specialist consultants. How this would be carried out for any service would depend on a number of factors, such as service priorities, funding, staff availability, training and support. Implementation research could examine different models of service delivery, based on integration of practitioner and parent perspectives in consideration of different service needs and structures.



## Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

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