



Child Chronic Illness and Parent Work-Family Conflict: Investigating the Experiences of Working Parents

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Abstract

Objectives Parents play a pivotal role in helping children manage their chronic illness, consequently taking on multiple roles. In such circumstances, parent inter-role conflict can impact parent and child aspects and outcomes (e.g., well-being). This study aimed to examine the work-family interface for parents of children with diabetes, asthma or eczema, by exploring their experiences in comparison to those of parents with children without chronic illness and those with diverse chronic conditions.

Methods Semi-structured interviews with fifteen working mothers (M age = 38.20 years; $SD = 0.91$) of children with diabetes, asthma or eczema were conducted.

Results From these interviews, four key themes were identified: (a) parent impact, (b) child wellbeing and development, (c) support, flexibility and understanding, and (d) broader impact. Mothers experienced conflict between work and family roles similar to that evidenced in past research. But unique to these parents is their ongoing carer role (e.g., not meeting the care needs of their child). Family impacted their work in various ways (e.g., sacrifice career opportunities), with impacts because of their carer role (e.g., taking more time off work) also illustrated. For these parents, the importance of support (e.g., from workplaces, family) is highlighted, as this alleviated the challenges and subsequent impacts experienced.

Conclusions More research is proposed to investigate the added demands faced by these parents, by quantifying these demands, given their importance in determining work-family conflict. As this study provides very preliminary findings, further research is required to address several of the limitations discussed.

Keywords Chronic illness · Family · Parents · Work · Work-family conflict

The common occurrence of dual-income families means that parents need to balance competing work, family and life responsibilities. This can lead to additional pressure and stress for parents, which can be further exacerbated when children have a chronic health condition. In Australia, 1 in 2 (50%) of individuals are estimated to have at least 1 of

8 selected common chronic conditions (e.g., cancer, cardiovascular disease, mental health conditions, arthritis, back pain/problems, chronic obstructive pulmonary disease, asthma, and diabetes). Nearly 1 in 4 (23%) are estimated to have two or more of these conditions (AIHW 2018). A medical condition is considered chronic if it has: a duration lasting, or is expected to last at least 6 months; a pattern of recurrence; deterioration and a poor prognosis and a negative impact on an individual's well-being (O'Halloran et al. 2004). These conditions can range from mild (e.g., minor hearing loss) to life-threatening (e.g. heart disease), however, in children allergic reactions/disorders (e.g., asthma or eczema), cystic fibrosis, cancer, and diabetes (Gale 2002) are most common.

For young Australians (aged 2 to 12 years), asthma (11% of children, 0–14 years: (AIHW 2016); Type One diabetes (T1D)—over 6000 children or 1 in every 720: (AIHW 2015), and eczema (around 38.5% or 1 in 3) children (Martin 2011) are most prevalent. Caregivers of these ill

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children must play the role of “health” carer with the added challenges of attending to their child. This exploratory research, using parent interviews, aimed to investigate these work, family and life challenges. Given the prevalence of the three illnesses mentioned, it is likely numerous parents are balancing multiple roles.

Chronic physical illnesses, such as T1D, asthma, and eczema are enduring health problems that can be managed but not cured. For young children, parents are faced with the primary responsibility for their child’s illness management until their child is cognitively and psychosocially able to self-manage (Brown et al. 2010). Effective management (self/family management) of an illness is a key factor predicting better child outcomes, making the extent to which an individual or individuals (e.g., parents, caregivers) meets the medical/treatment regimen a key determinant of clinical success (Gardiner and Dvorkin 2006). However, illness management involves specific tasks that parents need to perform.

For parents of children with T1D, there are three main components for treatment: medical nutrition therapy (MNT), which is a non-pharmacologic management approach that focuses on normalization of glucose, blood pressure, lipids, and weight. This means parents need to count carbohydrates (via food labels), measure portion sizes and monitor exercise/routine physical activity. Medication management or pharmacological management means that administration of insulin and associated knowledge of the types of regimens (e.g., Basal bolus therapy, multiple daily injections [MDI] or Continuous subcutaneous insulin infusion [CSII]) is required. Monitoring of blood glucose levels is also a key part of management that needs to occur multiple times a day. Prevention of complications such as hypoglycemia, with a need to employ problem-solving skills to determine the cause of the low blood glucose is also needed. A more detailed summary of these aspects appears in Beck and Cogen (2015). Important here is noting that each component can influence overall child outcomes. For asthma, parents need to understand treatment, how to monitor and respond to symptoms, and also guide their child’s self-management (Brown et al. 2010). The Australian Asthma Handbook (National Asthma Council Australia 2019) provides more current guidelines for the management of asthma in children. For those with eczema, a rigorous, daily skin treatment regimen is required along with avoidance of triggers and irritants and treatment of flares and episodes of severe eczema. The most recent guidelines on eczema treatments and good management are provided by the Australasian Society of Clinical Immunology and Allergy Limited (ASCIA 2019). As T1D, if not followed, the risk of further complications (Boguniewicz and Leung 2010) and the need for hospitalization (Ohya et al. 2001) is increased. Additionally, other tasks may

include: making adjustments to family lifestyles, managing and coordinating care with others (Brown et al. 2010), consultation/managing appointments with health professionals, while also tending to other family or work responsibilities (Buford 2005; Kieckhefer and Ratcliffe 2000).

From a broader perspective, the larger body of literature on stress, coping and management in families of children with chronic conditions also indicates the types of experiences faced. The Family Management Style Framework (FMSF) is an established framework developed by Knaf and Deatrick (2003) that describes the processes that families experience, the way they manage care challenges and the response patterns of these families. The FMSF has three components. The first being the “definition of the situation” or how parents describe important aspects of having a chronically ill child. This includes child identity (view of the child and their capabilities), illness view (understanding and beliefs related to the child’s illness, both technical understanding and subjective evaluation) and self-view (the ill child’s view of their health compared to peers). The second refers to “management behaviors” or the actions parents perform to manage the illness. These include: parenting philosophy (goals, strategies and behaviors relating to care for the ill child), management mindset (views on ease or difficulty in performing treatment regimen and the ability to manage effectively), management approach (orientation to management of child’s illness and associated behavior) and self-care behaviors (child’s participation in treatment regimen, behaviors and perception of abilities). Finally, the third aspect is of “perceived consequences” or how parents describe the impact of the illness on family life. This includes: parental mutuality (degree of holding similar views of situation and management approach), foreground (view of extent to which the illness is a dominant focus of family life), future dread (belief their family’s and child’s future wellbeing is extensively impacted by the illness) and child consequences (child’s perception of how the illness impacts their daily life). The variation across these aspects and related components and the underlying dimensions lead to a series of patterns relating to a family’s response. These are commonly referred to as “family management styles”. The styles of family management have been further investigated and revealed to be as follows: thriving, accommodating, enduring, struggling, and floundering. These are described at length by Knaf et al. (1996).

The “thriving” family management style is about “normalcy”. Parents view the child as normal, use an accommodative parenting philosophy, with the goal being to assure a normal life (e.g., encouragement of involvement in usual activities) and stressing that “life goes on”. They describe the illness as manageable, are confident in this management, and are proactive in their approach (e.g.,

planning, learning from prior experience). Major negative consequences are not described, as the illness is framed in terms of positive outcomes (e.g., the emotional closeness between family members). The “accommodating” style also centers around “normalcy”—although with identified challenges in managing the illness. Accounts about management vary, with some parents managing the illness well, while others identifying difficulties. Parents view the child as a tragic figure, whose life chances are compromised given the illness. However, the emphasis of the success in incorporating the illness into the family routine is present—with an accommodative parenting philosophy adopted and confidence in the management of the illness. Proactive management is also present, although there is a tendency for a more compliant approach (e.g., following doctor’s orders, careful monitoring of symptoms, treatment regimen, and behavior). Few negative consequences are reported, with the illness not at the foreground focus, although occasionally, parents expressed a sense of future dread for their child’s trajectory.

The “enduring” style centers around difficulty—in terms of situation and the extensive effort invested in illness management. Parent views about the child mirror the above, with additional feelings of guilt and regret. A more “sheltering” parenting philosophy is used—where parents focus on protection from harm, the importance of restrictions and teaching of ways to recognize and accept limitations. Although confident in their ability to manage the illness (usually adopting a proactive approach), time is focused on the “great” effort of adhering to treatment regimens, describing illness management as a burden. Their circumstance is described as an “inherently difficult situation”, with no ability to envision ways to make illness management less burdensome. Major negative consequences on family life are discussed, as the illness is at the foreground of life (e.g., an ever-present concern). The future is often viewed with a sense of dread.

The “struggling” style features parental conflict over the “best” illness management (e.g., differing illness views and expectations). Mothers particularly view the situation as more negative than fathers—with the illness an ominous situation, with future complications and a “hateful” restriction that decreases the quality of their lives. An accommodative parenting philosophy is common, although with little or no spousal support (e.g., insufficient involved in management, unappreciative of efforts). Fathers have a more “life goes on” attitude and see their child as normal, express confidence in providing care but with little evidence of doing so, and while being critical of their spouse in their management of the situation. The negative consequences on family life include the lack of agreement between parents and associated conflict, with the illness constantly in the foreground of the family life. The “floundering”

management style is determined by confusion and several negative parent experiences. The child is viewed as a tragic figure or as a problem child, with academic or behavioral problems, additional to the illness. Illness management is difficult, with efforts for effective management usually unsuccessful and management viewed a burden. The illness is an ominous/ hateful situation with parents expressing uncertainty in illness management, with an inconsistent or absent parenting philosophy (e.g., ambiguous parenting goals, such as wanting to be accommodating but having a protective stance). As a result, parents are described as feeling inadequate. Management of the illness is handled reactively, with prior experiences not integrated. Illness issues are managed when serious, with early interventions not recognized. The illness is viewed to be a negative situation that is impossible to manage effectively, with negative consequences on family life.

Costs for management of child chronic illness, whether medical or treatment-related, for parents of children with chronic conditions can be up to three times higher than the medical expenses of parents with a generally healthy child (Newacheck and Kim 2005) or those without a chronic condition. This increases the importance of employment and concomitant financial security. Although parents of children with chronic conditions/illnesses are employed or working, like most other parents (see Kish et al. (2018)), for them working can prove to be a potential barrier to providing effective child medical care. This is because participation in other roles (e.g., worker, parent, partner) can compete for their time and energy.

Competing demands of both “worker” and “parent” roles can lead to inter-role conflict whereby both roles are negatively impacted. This conflict refers to when pressures in one role are incompatible with the pressures that arise within another role (Kahn et al. 1964) and occurs when requirements and responsibilities of two roles or more compete for limited resources of an individual (Goode 1960; Kahn et al. 1964; Kopelman et al. 1983). Referred to as work-family conflict, this umbrella term is used to describe the conflict between family and work roles, which any parent can experience. It is a form of “inter-role conflict in which the role pressures from the work and family domains are mutually incompatible in some respect. That is, participation in the work (family) role is made more difficult by virtue of participation in the family (work) role” (Greenhaus and Beutell 1985, p. 77). As such, work-to-family conflict (or WFC: work interfering with family) would, therefore, be present when participating in a work activity interferes with participation in a competing family activity. Family-to-work conflict (FWC: family interfering with work), would occur when participating in a family activity interferes with participation in a competing work activity (Kahn et al. 1964; Netemeyer et al. 1996). The

additional role pressure or stress experienced in the caregiver role can “spillover” into other life domains (Anehsensel et al. 1995; Pearlin et al. 1990), as the added caregiving limits the number of resources devoted to other roles.

Research with working mothers of children without a chronic condition provides some indication of the types of experiences faced and the impact that this has on families and parents in general. A study by Haslam et al. (2015) found parent guilt (e.g., for not meeting all responsibilities, seeing their children enough), occupational stress (e.g., long hours, work deadlines), family restrictions (e.g., working after hours) and issues around being a good parent (e.g., pressure to do everything means more impatience with their children) to be common experiences. The need to balance meeting competing demands led to these mothers feeling “worn-out” and to sacrifice personal or social time. Having to care for their family also limited career opportunities. Positively, however, the limited time experienced led them to prioritize spending quality time with their children. Working also meant they had a “career”, opportunities to grow and interact with others and feel a sense of personal achievement (Haslam et al. 2015).

For parents whose children face chronic illness, meeting the demands of daily “care” of their child’s health condition, together with the demands related to work, family and personal life presents significant challenges, over and above those of parents of children without a chronic condition (Melnik Feinstein et al. 2001; O’Brien 2001). Several qualitative studies have explored the work and/or family experiences of parents with chronically ill children. Two studies (George et al. 2008a, 2008b) particularly focused on workplace experiences. These illustrated the negative impact of care responsibilities on parent work suggesting they may be over and above that experienced by parents of typically developing children. These mothers, in meeting competing demands, needed to rearrange working hours, use leave entitlements, work unsatisfactory hours, sacrifice their careers and change their jobs (George et al. 2008b). Additionally, Vickers et al. (2004) and Vickers and Parris (2005) detailed more general issues of mothers working full-time and acting as primary carers of their ill child. These mothers were expected “to do it all” –work, care for their sick child (e.g., make decisions about general development and their illness), manage their household (e.g., perform domestic duties) and look after the family (e.g., needs, well-being). As a result, these mothers reported feelings of overwhelm, exhaustion and strain. Feelings of uncertainty and fear for their child’s future wellbeing was a common worry, adding additional strain; with guilt also present (e.g., for the little time spent with other children, being involved in school activities, socializing or meeting work commitments). Many of these activities were not

possible given the time spent caring for their child’s illness. For some, feelings of anger surfaced at being judged by others. The limited support offered (e.g., flexible work arrangements, leave entitlements) (George et al. 2008a) and the negative and unsupportive attitudes of employers (e.g., uncaring) about the pressures and responsibilities they faced, and the lack of support and understanding from their partners or colleagues added to the challenge (Vickers et al. 2004). However, these studies focused on the experiences of parents with children who have diverse chronic conditions that differ dramatically in presentation. No research studies examining the experiences of working parents with the three most common chronic conditions/illnesses are available. Furthermore, these studies do not compare or contrast the experiences of parents faced with needing to meet the “health” carer role to parents that are not faced with such a role.

This research aims to focus on parents of children with T1D, asthma, and eczema. Furthermore, as no study with this group of parents was found, in this study we firstly aim to describe their experiences. Secondly, we will compare the specific experiences of these parents to past established research with parents of children without a chronic condition and those who have diverse chronic conditions, to outline any differences or similarities that might exist between these groups. This will be done by using a similar methodology and interview set to the study by Haslam et al. (2015), enabling the determination of any similar or different themes. Additionally, a discussion of what types of management styles apply to these parents will be provided. It should be noted here that while “parents”—both mothers and fathers were the focus, no fathers participated in this study. As such, the rest of this paper will focus on mothers.

Method

Participants

Parents were recruited through schools, specialist clinics, and illness-specific support groups across Australia. To be included in this study, parents had to: (a) be working at least 2 days a week, (b) taking care of a child aged between 2 and 12 years, with a diagnosis of T1D, asthma or eczema for at least 6 months and (c) be living in Australia. Parents were excluded if they did not meet all of the above eligibility criteria.

A total of 25 parents contacted the researcher over four months and were screened for eligibility via email. Of these, 10 parents failed to contact the researcher beyond initial interest and were declined. As these parents were excluded, the final sample of parents was fifteen, in this case mothers (M parent age = 38.20 years; SD = 0.91) with children

aged 4 to 11 years (M child age = 7.80 years; SD = 0.51). Parents had an average of 2 children, were married (93.4%) and educated (73.4% having a university degree or higher). Overall, 46.7% were employed in full-time work (≥ 35 h a week), while 53.3% were employed in part-time work. On average they worked around 30 h per week (M working hours = 29.87; SD = 2.64); with no significant group differences: asthma (M hours = 31.70; SD = 9.78), T1D (M hours = 27.92; SD = 8.80) and eczema (M hours = 30.50; SD = 14.75), $F(2,14) = 0.174$, $p = 0.843$.

The numbers of children across each illness were similar. Six children (all girls) had T1D (M child age = 8.00 years; SD = 0.63), with 5 (one boy, and four girls) having asthma (M child age = 9.60 years; SD = 1.14) and 4 (two boys, two girls) having eczema (M child age = 5.25 years; SD = 1.26). Overall child illness severity reported by parents on a 1 (very mild) to 10 (Unimaginable Unspeakable) scale was high (M = 7.03; SD = 2.15). Differences in severity based on illness type were found, $F(2,14) = 11.58$, $p = 0.002$. Those with T1D reported greater severity (M = 9.03; SD = 1.11), than both asthma (M = 5.90; SD = 1.25) and eczema (M = 5.37; SD = 1.80). Parents reported that, on average, their children had their illness for around 5 years (M = 5.10 years, SD = 2.04). Differences in duration based on illness type were found, $F(2,14) = 25.67$, $p < .001$. Parents reported their child with asthma had the illness for a longer time (M = 7.20 years, SD = 1.09), than those with eczema (M = 5.50, SD = 1.00) or T1D (M = 3.08, SD = 0.80).

Procedure

This study utilized a qualitative design using semi-structured 1:1 interviews. Ethical clearance was obtained through the School of Psychology review committee at The University of Queensland. Following the distribution of the information about the study, parents contacted the researcher, via email, and were screened for eligibility through email correspondence. Eligible parents were sent an information sheet outlining the study in more detail and an informed consent form to sign and date. Upon receipt of the signed consent, parents specified their preferred time and format (in-person v telephone) for the interview. All opted for the phone interview. For consistency, the first author conducted all the interviews. Interviews lasted an average of 42.5 min and were audio-recorded, then transcribed. Before the interview, the purpose of the study was outlined verbally to parents. Parents were also informed that they could respond as much or as little as they wished and were also assured that there were no wrong or right answers to the interview questions. After the interview, parents were thanked for their time and asked for their postal details for their reimbursement (\$25 gift card) to be forwarded.

Table 1 Interview question schedule

Interview questions
1. What are some of the good things, if there are any, about being a working parent of a child with chronic illness?
2. What are some of the challenges, if there are any, about being a working parent of a child with chronic illness?
3. Would you say that being a parent then impacts your work, and if this is the case, in what ways does this happen?
4. Would you say that your work impacts your parenting, and if this is the case, in what ways does this happen?
5. How does, if it does, raising a child with T1D, asthma or eczema and having to be a working parent impact your day to day functioning?
6. How does, if it does, you being a working parent and having a child with T1D, asthma or eczema, impact your child's quality of life and day to day functioning?
7. How do you think that your experiences compared to those of other parents, particularly those who don't have children with a chronic illness?
8. Is there anything else that was not covered that is an issue for working parents of children with chronic illness?

Measures

Eight interview questions were adapted from Haslam et al. (2015) and formed the framework of these interviews. These are provided in Table 1.

Data Analysis

The interviews were transcribed by the first author, then re-read by an independent researcher for accuracy checking. The transcripts were then analyzed using NVivo, Version 11, following the six-step thematic analysis procedure outlined by Braun and Clarke (2006): (1) data familiarization; (2) generation of initial codes; (3) searching for themes; (4) reviewing of themes; (5) defining and naming themes; (6) producing the final results to report.

Results

Thematic analysis of the interviews revealed 14 categories that were subsequently grouped to form four key themes (see Table 2). To assess the reliability of the primary coding, a second independent coder examined these categories, across four of the fifteen interviews. These were selected at random using a web-based, random number generator. The independent coder identified 12 of the original 14 categories across the four interviews. This produced a high level of inter-rater reliability, $\kappa = 0.79$ ($p < 0.001$), 95% CI [0.58–0.99] (Altman 1990). The four themes were identified as (a) Theme One: Parent impact; (b) Theme Two: child

Table 2 Full list of identified codes and themes

Theme 1	Theme 2	Theme 3	Theme 4
Parent impact	Child development and wellbeing	Support, understanding and flexibility	Broader impact
Care of child	Responsibility, understanding and independence	Personal support, understanding and flexibility	Other children and family members
Physical impact	Wellbeing and parenting of the child	Providing support and understanding to others	Parent workplace
Psychological impact			
Social impact and relationships			
Personal impact			
Work, family and time			
Occupational (work) impact			
Financial impact			

development and wellbeing; (c) Theme Three: support, understanding and flexibility; and (d) Theme Four: broader impact. The fourteen categories are also highlighted in Table 2.

During data collection, it should be noted that around the third interview with parents of children with each type of illness, the themes and answers to interview questions became fairly repetitive. At this point, it was concluded that the data collection reached saturation point. A small number of interviews still took place, given parent interest. For these interviews, similar themes and answers arose. Trustworthiness or validity of the interviews was also achieved through the use of record-keeping, a clear decision trail and consistent and transparent interpretations of data (Long and Johnson 2000; Sandelowski 1993) achieved using NVivo. Across the study, and groups of parents and within groups of parents similarities and differences across accounts were established to ensure different (and all) perspectives were represented (Morse et al. 2002; Slevin and Sines 2000). The inclusion of verbatim descriptions of participants' accounts to support findings, that are dispersed throughout the paper is also another strategy (Slevin and Sines 2000). The quotes used are those believed to be most relevant to the aspect discussed. As such, parents may have been quoted multiple times. The reporting of the results that follow and the associated procedures followed (as detailed above) are generally in line with the Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist as outlined by Tong et al. (2007).

Parent Impact

The first theme centered around mothers' reports of a range of impacts related to their work, care of their child's illness, and other roles (e.g., parent to other children) and numerous physical, psychological, personal, or social and financial

impacts. The mothers described illness management as "never-ending, ever-changing and unpredictable". They always needed to be prepared and available to deal with illness-related issues. However, in some cases because of needing to be at work, being always available was not possible, meaning that child and family responsibilities were not met.

Calls throughout the day, more planning and juggling issues related to their child's illness meant their days were described as "busier" and "tougher". Mothers highlighted that they always needed to do more in terms of caring for their child—being aware, constantly monitoring their child and considering consequences—when at home, at work and when the child was in the care of others. For some mothers, this was even more difficult as their work was impacted given the difficulty in finding childcare. For example, one mother said that "having diabetic children, it's a lot more difficult to be able to do all that stuff with work, due to not being able to have a babysitter on hand" (Mother of 4, 37, employed part-time; child: 8- year old with T1D).

Changes in work hours and roles, even careers, because of their child's illness were common. Reducing work hours and taking time off from work was most prominent, given the need to meet care responsibilities (e.g., attend appointments, deal with unexpected emergencies). As one mother described: "I had to resign from one job, by being a parent of chronically ill children" (Mother of 2, 43, working full-time; child: 7-year-old with eczema). Needing more time off to attend medical appointments and other activities with the child, led to some mothers feeling less reliable as a worker, feeling restricted to some occupations, to part-time work or saying no to work opportunities. In addition to other domestic duties, time away from work was spent attending appointments, dealing with agencies, researching treatments or educating others about the illness. Finding time for themselves was challenging, given that all else was a

priority. The illness was often described as an added burden leading to feelings of being “busy” and “rushed”. For example, one mother said that “there’s never enough time in the day to get things done” (Mother of 2, 39, working part-time; child: 4-year-old with eczema).

Worry and anxiety about their child were common. One mother described it as: “that extra, umm...stomach clenching, worrying inside of you around your child not being well” (Mother of 2, 41, working full-time; child: 10-year-old with asthma). Levels of worry and anxiety were even greater when the child was cared for by others. Although helpful as it allowed mothers to work, it usually meant a lack of control—having to “trust” others with their child, which led to great worry. Parents reported their child to be continually on their mind while at work, leading to great distraction or as one mother suggested, something that “you can’t just turn it off for a day” (Mother of 4, 37, working part-time; child: 8 years, T1D). For one mother having to be working and looking after her children led to psychological and physical “burnout”. In contrast, others said that working was a good distraction from the illness “because you’re not just sitting there dwelling on the fact that your child is unwell.” (Mother of 1, 42, working full-time; child: 8 years, asthma).

Feelings of guilt also surfaced and related to not spending enough time with their family (e.g., ill child or other children), for doing their job well because of the added worry or distractions related to their child and more personally due to repeatedly saying “no” to social commitments. Stress was expressed as “great” or “extra” due to the child’s illness (particularly when relying on others to care for the child) and because of needing to meet other family responsibilities (e.g. being there for other children). Sleep was also impacted because of the need to manage the child’s illness throughout the night and at times staying up to catch up on work. Constant exhaustion and feeling tired impacted on mothers’ moods and ability to cope with everyday basic routines (e.g., parenting), especially when working night shifts and having very little sleep (due to staying up with the child). This impact on parenting was summed up well by one mother who said: “I know that when I’m coming off night duty I don’t have, my temper is shorter than it normally is, and my tolerance is lower than it should be” (Mother of 3, 37, working part-time; child: 7 years, T1D).

On the positive side, work gave mothers a chance to have time out for themselves, to be around other adults and to have another role that they understood and had control over. It also gave them a sense of perspective, identity, and achievement. Through working, their child was provided with a good role model around how to hold commitments, work hard and contribute to society. As one mother described, working “shows them also that if you want

something you actually have to work to attain it” (Mother of 4, 37, working part-time; child: 8 years, T1D). In addition, being in both work and care roles, mothers felt they had a better understanding and more empathy for other parents in similar circumstances. Working also meant greater financial income and less financial worry allowing for better care of their child’s illness. Finally, social impacts were both positive and negative. For example, for one mother of a child with eczema, the impact of their child’s illness meant fewer visits to friends and fewer opportunities to develop social connections. For others, it meant interactions with other adults and traveling opportunities, as well as more support.

Child Wellbeing and Development

The second theme focused on the impact on child wellbeing and their development. The impact on such child aspects was seen as a consequence of the mothers working or because of the illness. This was across the child’s emotional, physical or social wellbeing or their development of independence and responsibility. In most cases, the impact on the child was limited in all aspects. Most mothers stated that they encouraged their child to “keep doing things”, instilled in the child that “because you’re unwell, it doesn’t mean that you can’t participate” (Mother of 1, 42, working full-time; child: 8 years, asthma) and that the illness (in this case diabetes) “shouldn’t hold you back” (Mother of 3, 41, working part-time; child: 8 years). For some children, mothers said that the illness is just the “normal”, while also stated that they made sure that everything was done so that the child can have “a childhood, where he’s not being robbed of the normal opportunities that kids have in childhood” (Mother of 2, 39, working part-time; child: 4-year-old with eczema).

Of the more negative impacts, firstly, mothers said that they felt needed more for their child’s emotional support, with many believing their child wanted them around more. For example, mothers reported that at times children became frustrated and upset because they could not be at home with them when sick or for not spending as much quality time together, which led to mothers expressing concerns their child sometimes felt abandoned. This is as one mother suggested “I think she would prefer me to be around more” (Mother of 2, 33, working full-time; child: 10 years, asthma). However, despite less time spent with their child than desired, many mothers tried to spend as much quality time with their child when possible. Even in this, some mothers viewed positives—in that they felt their child had greater social exposure with children and as such more opportunities to develop relationships with other people. As one parent described: “It is positive because I get to share my experiences about working with other people and going

to do different things outside the family home” (Mother of 2, 38, working part-time; child: 5 years, eczema).

Secondly, as the mothers were working, their child’s physical wellbeing was negatively impacted. As one mother of a child with eczema said, her being away at work often meant that her daughter was anxious, which only aggravated her eczema—“There are mornings when I drop her off and I see her scratching” (Mother of 2, 35, working part-time; child: 5 years, eczema). Being cared for by others also impacted children’s physical wellbeing due to the different approaches to illness management by those that cared for them. For one mother, her being at work meant that her son attended outside childcare—which often led to his eczema being impacted given the uncontrolled environment. She said: “I have the best handle on his skin and no one else does. And when I’m away from him, his skin suffers, as a result.” (Mother of 2, 39, working part-time; child: 4 years, eczema)

The child developing independence, especially in illness self-management, was a positive consequence that mothers felt was present and due to them working. Needing to be independent and self-sufficient in handling their illness was a consequence of mothers not being around all the time. As one mother stated: “I think that she’s had to be a little bit more self-sufficient when it comes to managing her illness when I’m at work.” (Mother of 2, 37, working part-time; child: 8 years, T1D). Developing responsibility, much earlier than most other children, was another impact. Specifically, their illness and their mothers working meant that children had to take on responsibility from a younger age, and to help with general, daily illness-related tasks.

Support, Flexibility, and Understanding

The third theme centered around support, understanding, and flexibility. Support specifically referred to having other individuals around to help—whether at work (e.g., employers, colleagues) or at home (e.g., partners looking after the children, helping with domestic chores), or from others like grandparents (e.g., to call on to look after the child given their illness), the community (e.g., back-up support or for costs of treatment) or the government (e.g., carer’s allowance, mental health schemes). One mother said that her actual work role provided her with more support, as in her job she worked with others who were supportive and understood her daughter’s illness. Mothers also expressed how grateful and lucky they felt to have this support. For example, as one stated: “I’m very fortunate to have a boss and colleagues that are very supportive” (Mother of 2, 35, working part-time; child: 5 years, eczema).

Having understanding and flexibility from employers was important. This usually referred to their employer understanding and being flexible with mothers when

needing to either take time off from work, to be working certain hours or days given their need to care, or to be taking calls while at work throughout the day or sometimes having children at the office. Understanding from family, other parents, or friends was also identified, but not at all times present. For example, one mother expressed that other family members, usually extended family, were less understanding about her child’s asthma—particularly its seriousness. Another mother said that other parents “who don’t have any knowledge of how it is to live with any kind of illness—make some very unhelpful comments” (Mother of 3, 37, working part-time; child: 7 years, T1D).

Having support, flexibility and understanding were important especially for mothers who were single parents or had no close family nearby or an involved partner. Support from partners, family and government help was sometimes unavailable. Government assistance was limited for treatments and medications due to changes in regulations—for example in terms of the conditions needed to subsidize asthma medication. One mother suggested that implementing family-friendly workplaces, especially for women who were working might be helpful to all women. Another said that some form of assistance for time-off was something that would help. Mothers also said that their work roles allowed them to provide support and understanding to others who were in similar situations, given their personal experiences.

Broader Impact

The fourth and final theme was the wider impact that mothers identified their situation to have on others—especially their other children and family members, and those in their workplace. The impact on other children centered around mothers feeling that other children sometimes were forgotten, given less attention and spent less time with as opposed to their chronically ill child. Concerning this, mothers expressed guilt—as one mother explained: “the guilt of not having much time with the other two children.” (Mother of 4, 36, working part-time; child: 8 years, T1D). Mothers working meant that other family members were also required to provide care for the child’s illness. Their partners were also impacted, as one mother said, “my husband will look after the kids a lot or take time off work, umm... where it’s needed” (Mother of 2, 41, working full-time; child: 10 years, asthma), showing that partners often had to pick up on housework and childcare.

In terms of the workplace, six of the mothers said that they felt they let their workplace down because of their need to take time off. In doing so, this added strain on their employers as it meant replacements were required and alternative arrangements made. Mothers said that they would be behind in doing their job as they often had to

leave work early or not be there. Clients and colleagues were also impacted as taking time away from work meant letting down clients or having to ask colleagues to take on additional work.

Discussion

This study aimed to examine the work-family interface for parents of children with diabetes (T1D), asthma or eczema and to compare and contrast their experiences to those already established in past research for both parents of children without a chronic condition and those caring for children with diverse chronic conditions. Interviews with a group of working mothers of children with these illnesses revealed four key themes: (1) parent impact, (2) child wellbeing and development; (3) support, understanding and flexibility; (3) and broader impact. This study adds to the current literature as it identified the unique experience of working parents of children with the three most common child illnesses in Australia and examined the impact of meeting multiple roles (e.g., health carer, parent and employee). These aspects have not been the focus of past research.

We now highlight the similarities and differences between the reported experiences these mothers faced and those reported by past research. Work impacted on their parent role (e.g., parenting) and other family members (e.g., other children, partners) in a way similar to those reported by past research on parents of children without a chronic condition. Work impacted family life because of needing to meet work responsibilities, sometimes long hours, or work certain jobs at certain times, leading to less time spent at home. Yet the impact of work on the care parents provided for their children was more evident for these mothers, as opposed to those of children without a chronic condition. This was particularly illustrated through experiences of not being always available for their child's illness-related issues or care due to work commitments. The care of the child and their illness was a common aspect mothers discussed and referred to throughout the interviews. Some said that they would need to rely on others to care for their child (e.g., fathers, grandparents), a challenge in itself, as childcare is often difficult to find. This often led to their child's health being impacted, as these other carers were not as well versed in the care of their child. However, mothers also felt that because of working and not always being around, their children benefited, as they learned how to be more responsible and independent, in life skills, but also most importantly in the way they handled their illness.

For these parents, the impact of their family on work seemed to be more substantial. This was specifically due to the carer role and associated responsibilities they had to

meet. It can be described to be both personal (relating to the parent), but also with others (employers and colleagues). Similar to past research with chronic illness (Vickers and Parris 2005), these mothers needed to be available to their child, be the first point of contact, take calls at work, rearrange working hours and take time off work. Some also needed to work in a specific type of work or to work certain hours because of a need to prioritize family and carer roles, rather than their careers. The latter experience is similar to the experiences of most mothers, who often report that having a family limits career opportunities, as they need to be there for their families (George et al. 2008b; Haslam et al. 2015). For this particular group, however, the constant need to be available for their child and difficulties in finding childcare seemed to leave mothers with no choice but to prioritize family and carer roles, despite this coming at a cost to their career aspirations. Their carer responsibilities also impacted colleagues and their workplace, placing strain on both groups—with their employers having to make alternative arrangements and their colleagues to take on extra work in their absence.

Although work had negative impacts, it also allowed these mothers an opportunity to have time away from dealing with their child's illness, providing a distraction, and a chance for interactions with others, while also developing a sense of personal achievement. In having the experiences of caring for a child with an illness, they also said they were more understanding and empathic with other parents, especially those in similar situations. For some, the shortage of time sometimes put things into perspective—with mothers feeling that it was important to spend as much quality time with their children as possible.

Guilt was present both in terms of work and family. Family-wise it was centered around not spending enough time with their children or for not being there for their family; much in line with the study by Haslam et al. (2015). More specific to these parents is the guilt they feel for not spending time with other children, feeling like they are neglecting them given the need to care more for their ill child. Unique to these mothers is also the guilt they expressed for not doing their job well, because of the worry and distraction they experienced for their ill child. Always worrying about their child meant being distracted leading to higher levels of stress, less productivity at work and greater guilt. Although this type of worry might be typical of most parents, the constant worry for their child's well-being throughout the day is an aspect that is more specific to these parents. It is important to make note of this here as it is something specifically related to having a child with an illness. Parents do report significant worry about their child with T1D (Streisand and Monaghan 2014), especially when children are unable to appropriately manage their illness. Most important is that this worry can have a further impact

on other aspects—particularly causing poorer parent-reported quality of life (Herbert et al. 2015) or as highlighted in this research, an impact in terms of guilt. As with the mothers of children with diverse chronic conditions, guilt also centered around not being able to make other commitments. So, while similarities can be identified within both groups of parents, it appears that the source of guilt is not only due to working too much or spending time with their family, but also because of the added layer of the child's illness (e.g., neglecting work and other children because of needing to care).

Finding a way to “juggle” the numerous competing demands meant always feeling worn-out, overwhelmed, exhausted and under great strain. Personal time was usually sacrificed, like other parents, however for these mothers there was always the “extra” strain of everything related to their child's illness, their work, and other family responsibilities. This finding is similar to past studies of children with chronic conditions (Vickers et al. 2004)—where the added burdens (e.g., attending appointments, hospitalizations, tending to the child throughout the night), but also being responsible for other family members and domestic duties, were present. Ultimately, this meant less time available for themselves, resulting in sacrifices to personal/social time.

Having support, flexibility and understanding from their employer or families were aspects present for the majority of these mothers. This is contrary to previous studies (George et al. 2008a; Vickers and Parris 2005) with chronically ill children illustrating that very little to no support exists for these parents, and others illustrating that little help is offered to support carers who struggle to meet their roles (McGrath 2001). Most who reported support felt that they were “lucky” to have this available and that it helped to alleviate stress levels and to better balance their responsibilities. This mirrors established research that shows having family-friendly work conditions (e.g., flexible hours, ability to take time off,) are all major contributors to achieving a positive work-family balance (Gornick and Meyers 2003; Gray and Tudball 2002; Prior and Richardson 2005). However, it is pointed out here that potentially this study recruited an educated sample of parents who perhaps may have been more equipped to access support. It may also be that, as these are very common illnesses, there is more awareness of these conditions and their implications.

In terms of the broader perspective relating to stress, coping and management, there are some similarities to the Family Management Style Framework (FMSF). This is specifically relating to the processes that families experience, the way they manage care challenges and their response patterns. Although difficult to specifically compare, as the main aim of this study was to explore parent experiences, some aspects can be discussed here, that

appeared across the four themes and could be loosely identified as similarities. It is important to note here that the impact of care was not the main focus, as such, but rather it was the impact of both the care and having to work that was the key focus. However, for example, parents described similar views as in the FMSF in terms of aspects such as child identity in that they seem to view the child as generally normal, wanting them to have a “normal” childhood or the illness view—described as an added “burden”, although most parents seemed to have a “life goes on” attitude, doing their best to not let the illness impact them and their families. In terms of the child's self-view, it is difficult to fully conclude how children viewed their illness, as these interviews here were with parents. However, it was illustrated by mothers that most children had to develop responsibility and independence much earlier than other children, which does suggest a potential comparison to peers.

As mothers mention that they do whatever possible to give their child a normal childhood—it could be said that comparatively, mothers are “accommodative” in terms of their parenting philosophy. Management of the illness, as “never-ending, ever-changing and unpredictable” and described as always having to do more in terms of caring for their child (e.g., being aware, constantly monitoring their child and considering consequences) somewhat mirrors experiences of parents in the “accommodative” or “enduring” family management style. Approach to management of the child's illness could be said to be “proactive”, as in the “thriving” and “accommodative” style, given the mention of always needing to be prepared and faced with more planning. In terms of the child, and their self-care behaviors—it appears that children are participants in their illness and associated management, as mothers discussed the need for their child to develop independence, responsibility, and self-sufficiency in handling their illness because of their parent not around all the time.

Finally, concerning the “perceived consequences” of the illness on family life, parental mutuality issues may have been present, as mothers had to work and the child was looked after by others—including partners. As to the illness being described as in the foreground of family life, mothers illustrated a need to do more in terms of care. However, the extent of this cannot be determined. Future dread was not particularly discussed, however, worry and anxiety about their child were common, although perhaps not to the same extent as in the “floundering” family care management style. As for child consequences, there were both positives and negatives, but only from the perspective of their mothers. Negatively, because of work they felt that the child needed them around for emotional support, saying their child wanted them around more, with children said to be frustrated and upset because their mothers could not be at

home with them when sick or for not spending as much quality time together. Certainly, while the child's physical wellbeing was negatively impacted when the parent was away at work (e.g., child anxiety impacting illness), the child's social wellbeing and their need to develop independence and responsibility could be considered to be positive outcomes.

Strengths, Limitations and Future Research

This is likely one of the first research studies that has focused on aiming to outline the experiences of working parents with young children who have T1D, asthma, and eczema and investigate whether these are similar to those described in past research. In doing so, it, therefore, adds to the current literature by its specific focus on this group of parents. It is important to focus on these illnesses given their prevalence and the little research conducted to date. To our understanding, this is likely the first research study to particularly focus on these parents and to empirically validate the anecdotal reports about the experiences they face and how this manifests in terms of balancing work and care of a child with an illness. Another particular strength of this study is that conducting interviews allowed for an opportunity to explore work-family conflict experiences and associated challenges, leading to a better and deeper understanding of how conflict can manifest. Due to the exploratory and descriptive nature of this topic, this approach and design were the best to communicate the depth of parents' or rather in this case mothers' experiences. The use of open-ended questions and probing allowed parents to respond in their own words and give specific examples. This allowed for richer information to be obtained, and for a better understanding of the issues faced.

There are however limitations to this study. The first is the use of a small sample of convenience, specifically educated mothers. As these mothers were recruited through existing groups such as schools, support groups or subject pools (Patrick et al. 1998), it is likely that a positive bias of sort may have occurred—with mothers being more educated, from higher socioeconomic status (SES) and perhaps more positive in their perceptions of the importance of research (Dodge et al. 1993; Wagner et al. 1991). This limits the generality of the findings; however, the sample size is viewed as acceptable for qualitative research (Dworkin 2012; Guest et al. 2006). The marital status of the mothers in this study (as most were married) is also a factor that may need further investigation. While it is most likely that more support is present if mothers are married, notably, marriage does not always equal increased support. In fact, it could lead to stress if parents disagree over approaches. Future work is needed to examine if these patterns would

emerge, for example, with fathers, single-parent families or less educated parents.

Secondly, although this study is intentionally qualitative, it does not allow for conclusions to be made on the extent to which levels of work-family or family-work conflict are different from that of other parents. Rather this study provides important insight regarding what parents report to be the added demands and responsibilities related to their child's illness, and how this could play a role in creating greater conflict. Demands play a key part in parent work-family conflict experiences. It has been documented that demands are predictive of the level of conflict experienced, whereby greater time spent in family activities, increases family demands, with the responsibilities associated with caring for children and aging parents, for example, commonly associated with high levels of family-to-work conflict (Anderson et al. 2002; Byron 2005). A potential focus of future research could be to conceptualize and quantify these care demands and their impact, to investigate how these may impact parents in terms of work/family conflict, and even potentially contribute to the literature on the variation in management of the illnesses of focus here. It would be warranted to particularly see if the three illnesses are similar or different in the level of demands required by parents—especially given that as outlined above in the introduction, all three require different self- and family-management behaviors. It is also important to point out that the focus of this study was on parents of younger children. Here, the role of illness responsibilities falls to parents. It is very likely that as the child grows, he/she begins to build independence and autonomy as related to their illness. Certainly, it would be warranted to look at this difference in the age of the child. The focus of some future research could be to conduct another study with a group of mothers of children aged 12 and over, or perhaps follow up with these mothers at a later date. This would mean looking at this over time and would also allow this distinction to be made.

Finally, although not specifically mentioned, mothers did allude to resilience and a desire not to be defined by their child's diagnosis. As such, the resilience of both parents and children would be a factor that requires further investigation. Certain characteristics such as level of SES, family rhythm (e.g., rules, rituals) and the family's ability to reconstruct their conception and understanding of their child may impact their level of resilience. For the ways this occurs and further details, see Knestrict and Kuchey (2009). All three of these aspects are potential factors to investigate. Walsh (2003) also proposes several key processes in family resilience. These fall broadly under three domains: family belief systems (making meaning of adversity; positive outlook, transcendence, and spirituality), organizational patterns (flexibility, connectedness, social and economic resources) and communication/problem solving (clarity,

open emotional expression, collaborative problem solving). In line with the previous limitation, it would also be warranted to track families over time to determine which of these factors perhaps predict better resilience or independence. Certainly, these are all aspects that require further investigation, as all contribute to resilience. This discussion certainly points to the notion presented by recent research which illustrates variations in family functioning— with some reporting good and others poor functioning in families. Therefore, it is noted here that most, however, not all, families manage a child’s chronic condition with a minimal negative impact on their life (Herzer et al. 2010; McClellan and Cohen 2007) with variations likely given multiple aspects (e.g., illnesses requiring different self- and family-management behaviors).

This study illustrates that mothers of children with the identified illnesses experience work-family conflict, with many identifying instances of how either their work impacts their family responsibilities (including their carer role) and how family impacts their work responsibilities. While some of the examples are similar to those reported by parents of children without a chronic condition (e.g., work/wellbeing impact, guilt, quality parent), others are specific to this group. This includes, for example, the impact on work in terms of taking time off/leave or calls during the day to care for the child. The comparison throughout this paper with the experiences of parents illustrated in past research might suggest that all parents are experiencing work-family conflict regularly, although perhaps to differing degrees. However, this study did not focus on quantifying this conflict. Although both types of conflict are reported here, perhaps family-to-work conflict for these parents is greater given the added care demands they face. This is an area for future quantitative research.

The experiences of exhaustion and strain suggest that perhaps mothers are impacted in terms of their well-being to a greater extent than other mothers. This too remains open to further investigation. Greater conflict and stress has been linked to a negative impact on parent functioning (Byron 2005). This may mean that parents who are not coping or functioning well because of more challenges would also be faced with difficulties in managing their child’s illness, which likely can have an impact on the child. Given the novelty of this research, further investigation must take place to examine the “extra” demands faced by these parents. Furthermore, quantifying and investigating differences compared to parents not facing these additional responsibilities would also be warranted. Findings from this and future research may be used to further highlight the demands of working parents of chronically ill children. They can also be used to educate family, school, and work communities of the added responsibilities that these parents

face and the potential consequences for child and parent well-being.

This study has provided evidence for the work-family research and literature by highlighting the challenges working mothers of children with T1D, asthma and eczema face in balancing multiple roles. The themes extracted and discussed suggest that although some of the challenges faced by these mothers are similar to those of other parents, the role of “health carer” further creates demands on parent presence and time, making life more challenging. Notably, however, while this seems to be the case given the examples and anecdotes here, this evidence is preliminary and requires further research. Addressing the limitations discussed above would be a starting point. Quantifying and measuring experiences, and further comparing if demands, work-family conflict, and parent and children outcomes differ based on whether parents have the additional role responsibilities of health carer are a few avenues, amongst others, for potential future research.

Data Availability

Due to ethical constraints, data for this study cannot be made openly accessible.

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Author Contributions Author A.K. contributed to the conception and design of the study, recruitment of parents, conducting and transcribing of the interviews and conducting of the thematic analysis, and drafting of the manuscript. Author D.H. contributed to the study’s conception and design—particularly advising on the processes needed to conduct interviews, transcription of data and the thematic analysis, and its interpretation; as well as critically reviewing the manuscript. Author P.N. contributed to parts of the conception and design of the study and provided feedback on ways to revise this manuscript.

Compliance with Ethical Standards

Conflict of Interest The Parenting and Family Support Centre is partly funded by royalties stemming from published resources of the Triple P—Positive Parenting Program, which is developed and owned by The University of Queensland (UQ). Royalties are also distributed to the Faculty of Health and Behavioural Sciences at UQ and contributory authors of published Triple P resources. Triple P International (TPI) Pty Ltd is a private company licensed by Uniquist Pty Ltd on behalf of UQ, to publish and disseminate Triple P worldwide. The authors of this report have no share or ownership of TPI. D.H. receives royalty and consultancy fees from TPI. TPI had no involvement in the study design, collection, analysis or interpretation of data, or writing of this report. D.H. holds an honorary appointment at UQ, P.N. is employed by UQ and A.K. is a former student at UQ.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional (School of Psychology Ethical Review Committee, The University of Queensland) and/or national research committee and

with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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