Caregiving, single parents and cumulative stresses when caring for a child with cancer

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Abstract

Background Single parents whose children have cancer are a marginalized group who report less family centred care, and therefore, less quality cancer care for their children. As such, the aims of this study were to explore how single parents of children with cancer describe their caregiving experiences and to understand their contextual life stressors.

Methods A constructivist grounded theory method was used. Qualitative interviews with 29 single parents of children with cancer who were at least 6 months post-diagnosis were recruited between November 2009 and April 2011 from four hospitals across Canada. Line-by-line coding was used to establish codes and themes and constant comparison was used to establish relationships among emerging codes and conceptual themes.

Results The first set of findings report on caregiving duties including: emotional tasks, informational tasks and physical tasks. The second set of findings report on the contextual picture of parent’s lives including their living conditions, their physical and mental health and their family histories of disruption, trauma and disease.

Conclusions Single parents caring for children with cancer were found to experience several cumulative stressors in addition to the current strain of caring for a child with cancer. The synergy of these cumulative stresses with the added strain of caregiving for a child with cancer may have long-term health and financial implications for parents. Broad-based policy interventions should focus on relieving the chronic strains associated with being a single parent of a child with cancer.

Introduction

Paediatric cancers are largely curable, with a 5-year survival rate of over 80% (Ries et al. 1999). Nonetheless, the treatment trajectory and its aftermath can be emotionally and physically intensive for patients and their families. During treatment, children may be frequently hospitalized, may undergo invasive surgery, experience pain, and are often treated with chemotherapy and radiation. Moreover, childhood cancer can be a chronic illness with treatment that can last for several years and that can cause a range of long-term effects in children (Young et al. 2002). As such, a diagnosis of paediatric cancer can cause substantial financial, emotional and physical strains on families, in particular on children and their primary caregivers (Van...
Caregiving stressors may be a particular challenge for single-parent families because they are often the sole adult balancing the emotional, physical and financial strains of caring for their families. Single parents are more likely to experience significant social and economic disadvantage than two-parent families (McQuillan 1990; Holden & Smock 1991; Lipman et al. 1997). Moreover, single-parent families must also balance the strains of work and family life while sometimes living on the margins of poverty (Avison 1995; Lukemeyer et al. 2000).

In the context of childhood cancer, the Canadian trend towards early hospital discharge has shifted the burden of care to parents in the home for many cancers. Children with cancer experience a range of side effects that parents may need to manage including fever and infections, nausea and vomiting, pain, fatigue, anxiety and depression. Moreover, parents as caregivers must administer medication, monitor for treatment side effects, bring their child to the hospital for medical care, and provide emotional support for the child with cancer (Keegan-Wells et al. 2002; Young et al. 2002; Klassen et al. in press). Additionally, while caring for a chronically ill child, parents must continue to financially and emotionally provide support for their family including other children living in the household (Mullins et al. 2010).

Brown and colleagues, in a 2008 literature review, called single parents of children with chronic illness ‘an understudied phenomenon’. These authors indicated that while the literature has examined the stressors associated with parenting an ill child, including the impact of illness on family finances, family roles, and caregiver burden, few studies have examined the stressors stemming from being a single caregiver of a child with a chronic disease. One study looking at single parents caring for a child with cancer found that single parents have high levels of distress that remained stable 6 months after diagnosis (Dolgin et al. 2007). A more recent study found that single mothers whose children had a chronic illness, including cancer, had higher levels of parenting stress when compared with married mothers (Mullins et al. 2010).

### Methods

#### Study design & participants

A constructivist grounded theory approach was used (Charmaz 2006). A purposive sample of 29 single parents was recruited between November 2009 and April 2011 from four Canadian paediatric oncology centres. We interviewed single parents of children with any type of cancer if: the child was at least 6 months post-diagnosis and was not considered palliative; the parent was the child’s primary caregiver, defined as the parent most responsible for the day-to-day care and decision making for the child with cancer; and the parent was a single parent, defined as the only adult living in a household with one or more children (including the child with cancer) for at least a 6-month period while the child was receiving cancer treatment. Sample characteristics for caregivers and their children are presented in Table 1. Ten parents who initially agreed to hear more about the study were not interviewed. Out of the 10, one participant was not at home at the appointed meeting time and was not reachable by phone afterward; four were not reachable by phone to hear more about the study and did not return messages; three were ineligible because they did not meet the study criteria; and two declined participation. Reasons for declining participation included an unexpected death in the family and because it was not a good time for the potential participant to meet for an interview.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N = 29 (%)</th>
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<tbody>
<tr>
<td>Caregiver age in years</td>
<td>41 (22–61)</td>
</tr>
<tr>
<td>Female</td>
<td>24 (83)</td>
</tr>
<tr>
<td>Male</td>
<td>5 (17)</td>
</tr>
<tr>
<td>Marital status at time of child’s diagnosis</td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>8 (28)</td>
</tr>
<tr>
<td>Separated</td>
<td>4 (14)</td>
</tr>
<tr>
<td>Widowed</td>
<td>5 (17)</td>
</tr>
<tr>
<td>Single (never married)</td>
<td>12 (41)</td>
</tr>
<tr>
<td>Other children at home</td>
<td>15 (52)</td>
</tr>
<tr>
<td>Highest level of education (n = 27)</td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>12 (44)</td>
</tr>
<tr>
<td>College</td>
<td>7 (26)</td>
</tr>
<tr>
<td>University</td>
<td>8 (30)</td>
</tr>
<tr>
<td>Annual household income (n = 23)</td>
<td>43K (0–91)</td>
</tr>
<tr>
<td>Current work status</td>
<td></td>
</tr>
<tr>
<td>Unemployed (full-time caregiver)</td>
<td>17 (59)</td>
</tr>
<tr>
<td>Part-time</td>
<td>3 (10)</td>
</tr>
<tr>
<td>Full-time</td>
<td>9 (31)</td>
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<tr>
<td>Child</td>
<td>N (%)</td>
</tr>
<tr>
<td>Male</td>
<td>19 (66)</td>
</tr>
<tr>
<td>Female</td>
<td>10 (34)</td>
</tr>
<tr>
<td>Child age at diagnosis in years, Mean</td>
<td>9 (3 months to 17)</td>
</tr>
<tr>
<td>Cancer type</td>
<td></td>
</tr>
<tr>
<td>Leukaemia</td>
<td>17 (59)</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>4 (14)</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>3 (10)</td>
</tr>
<tr>
<td>Neuroblastoma</td>
<td>3 (10)</td>
</tr>
<tr>
<td>Wilms’ tumour</td>
<td>2 (6)</td>
</tr>
<tr>
<td>Treatment status</td>
<td></td>
</tr>
<tr>
<td>In follow-up</td>
<td>11 (38)</td>
</tr>
<tr>
<td>In active treatment</td>
<td>18 (62)</td>
</tr>
<tr>
<td>Relapsed</td>
<td>5 (17)</td>
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</table>
Procedure

Approvals were obtained from the Research Ethics Board at each participating healthcare centre prior to starting the study. Participants were approached by a research nurse, clinical research associate, or paediatric oncologist to obtain consent. If a parent agreed to participate, the research team was notified and followed up with a telephone call to schedule an interview. All interviews were conducted by experienced qualitative researchers. Informed consent and participants’ agreement to the interview being audio-recorded were reconfirmed at the beginning of each interview. We used a semi-structured interview guide with questions designed to encourage parents to discuss their feelings and experiences in-depth. Interviews were recorded and transcribed with all identifiable information removed from the transcripts.

Data analysis

Charmaz’s (2006) method for coding and analysing qualitative was followed. Data collection and analysis took place concurrently, which allowed the research team to revise the interview guide and to gather data to elaborate and refine emerging categories. Analysis involved line-by-line coding and was inductive, with codes and categories emerging from participants’ narratives. Codes generated during the early phase of the analysis tended to be more descriptive and reflective of the content of the participants’ words, but as the analysis unfolded, higher order codes capturing implied meanings and more abstract concepts were created. Focused and theoretical coding was used to sift through large amounts of data and to strengthen initial codes. Constant comparison was used to examine relationships within, and across codes and categories. The final coding scheme was developed through ongoing discussions with members of the research team. Data collection stopped when the team determined that we had reached saturation and that no more new codes were created. Nvivo 8 computer software (2008, QSR, International) was used to organize the data.

Results

Parent and child demographics are summarized in Table 1. We begin our findings with a descriptive outline of the caregiving duties involved with caring for a child with cancer. These duties fell into three categories: emotional tasks, informational tasks and physical tasks that are distilled in more detail below. The second set of findings outline the contextual picture of parent’s lives including their living conditions, their overall physical and mental health and their family histories of disruption, trauma and disease before and during the time they were caring for their child with cancer. Table 2 lists the most prominent contextual stressors that single parents reported in their interviews (in addition to caregiving for their sick child) that are explained in more detail below.

Caregiving tasks

To illustrate the experience of single parents caring for a child with cancer, we provide a descriptive outline of the caregiving duties reported by parents in the day-to-day care of their sick child. We note that while many of these caregiving tasks are not unique to single-parent families, single parents had to manage these duties on their own, frequently without the financial or

<table>
<thead>
<tr>
<th>Table 2. Stressors reported in sample</th>
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<tr>
<td>n (%)</td>
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<tr>
<td>Living conditions</td>
</tr>
<tr>
<td>Financial strain</td>
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<tr>
<td>Fear of homelessness and/or not being able to pay rent or mortgage</td>
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<tr>
<td>Government financial support</td>
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<tr>
<td>Employment insurance</td>
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<td>Welfare</td>
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<tr>
<td>Public housing</td>
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<tr>
<td>Geographic and housing instability</td>
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<tr>
<td>Change in residence</td>
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<tr>
<td>Split families because of child’s illness or conflict in families</td>
</tr>
<tr>
<td>Overall health</td>
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<tr>
<td>Mental and physical health</td>
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<tr>
<td>Physical health</td>
</tr>
<tr>
<td>Depression</td>
</tr>
<tr>
<td>Anxiety</td>
</tr>
<tr>
<td>On antidepressants</td>
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<tr>
<td>Family histories</td>
</tr>
<tr>
<td>Family disruption</td>
</tr>
<tr>
<td>Divorce</td>
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<tr>
<td>Death of close family member in last 5 years</td>
</tr>
<tr>
<td>Abusive relationships</td>
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<tr>
<td>Contact with social services</td>
</tr>
<tr>
<td>Inconsistent ex-partners (coming and going)</td>
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<tr>
<td>Jail term (partner or family member in jail)</td>
</tr>
<tr>
<td>Family trauma &amp; disease</td>
</tr>
<tr>
<td>Murder or suicide</td>
</tr>
<tr>
<td>Death of close friend</td>
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<tr>
<td>Death of spouse</td>
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n represents the number of participants who endorsed the stressor in their interviews either prior to or during the diagnostic and treatment trajectory of the cancer treatment.

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emotional support of a partner or an ex-partner. As such, while the caregiving tasks that include both the demands associated with a cancer diagnosis and the maintenance of a home are similar for two-parent families, for single parents meeting these demands were significantly more burdensome. For example, a diagnosis of childhood cancer requires around the clock care for the sick child. In two-parent families, one parent is able to continue to work and provide financial stability for the family, while in single-parent households this is often not feasible. Other examples of the impossibility of ‘being in two places at one time’ include the necessity of continuing to provide care for other children in the family while also being with the sick child in hospital. We include these descriptive findings here as an entry point into the experience of single parents caring for a child with cancer and the tasks they were charged with dealing with almost entirely on their own. These tasks fell into three domains: (1) Emotional Tasks involved the affective duties of caring for a child with cancer; (2) Informational Tasks involved the educational, informational, and resource-seeking duties involved with childhood cancer; and (3) Physical Tasks involved the physical caregiving tasks that parents engaged in to care for their sick child and other children in their family.

(1) Emotional tasks

Single parents described the emotional tasks of caregiving as being particularly challenging. Such tasks included acting as the ‘emotional barometer’ for their families, for their communities and for their child. Parents described this experience as needing to put on a facade that ‘everything is under control in order to assuage the fears of their family members and people within their wider community and dealing with other people’s distress in response to the cancer diagnosis and treatment. For example, parents explained:

26: My brother and my sister just moved in with me . . . It affects them ‘cause they’re sad and they don’t want her to be sick, you know, but I stay pretty strong ‘cause I don’t show them my emotions I just kind of like take control of it and I kind of show them that it’s going to be okay.

29: My mom had cancer twice before, this was the third time for her and when he was first diagnosed it was only six months after the surgery she had for the second time she had cancer. And trying to tell her, a way to tell her that her grandson had cancer was the worst. ‘Cause I didn’t want her to get upset, because then she would get him upset. Other challenges included dealing with the emotional volatility of their child, who, because of medications, or because of feeling sick, could be moody, angry or frustrated. The emotional tasks also encompassed dealing with the emotional impact of diagnosis on other children in the family and providing support for their sick child and their extended family and friends. Participants described these tasks as follows:

1: She said ‘mom, it’s not worth it’ (crying) . . . She just felt so lousy and I thought, ‘oh we’re not even half way through and it’s going to get so much worse’ . . . I’m thinking ‘you don’t think it’s worth it now’, and you know what . . . if her prognosis like isn’t good, is it worth it? I’m trying to tell her you know ‘it’ll be okay’ but, is it?

24: He was in quite a bit of pain and he couldn’t walk. And you know, I really felt like I kept on having to tell myself that this medication is helping him even though it looked like it was really hurting him. That was really rough. And then near the end I guess when they when they finished the steroids they kind of go through almost a withdrawal . . . When it’s coming out of their system, so he was like screaming in pain and I couldn’t help him.

(2) Informational tasks

Single parents described a number of information-seeking tasks involved with caring for a child with cancer. These included administrative duties such as coordinating and scheduling healthcare appointments, filling out forms and managing cancer-related financial issues (e.g. completing reimbursement forms and/or applying for employment insurance); and information/educational seeking tasks such as learning about childhood cancer and its treatment, and seeking information about available resources. Other informational tasks involved attending to the educational needs of their sick child who may be missing school for extended periods of time. Parents talked about their day-to-day activities as follows:

2: I was going back to all my friends that I’ve got through the Internet and typing and explaining everything . . . explaining every single detail of what’s happening . . . So basically I was teaching what I was learning . . . I even had to explain like to my own family.

22: A typical, normal really busy day . . . I can’t really work as much ‘cause we have appointments during the week as well so I’m more limited to only being able to work a maximum of four days a week cause we have psychology, speech therapy, doctors appointments.
When the teacher is over and he has to do his math homework and schooling and that he’ll fight with me and say he doesn’t need it and I make him do his schoolwork.

(3) Physical tasks

Caregiving for a child with cancer involved both technical care duties (e.g. central venous line site care, administration of medications, monitoring of treatment side effects such as temperature) and caregiving tasks associated with treatment. Caregiving tasks included, for example, transporting and accompanying child to medical appointments and procedures; arranging for childcare for the child with cancer and their siblings; taking care of their child at home which could include duties such as carrying their weak child around the home or outdoors, bathing and feeding their child, and ensuring their child was properly nourished. For instance, participants described their caregiving tasks as involving many physical tasks:

26: She had a line in her chest and it needed to be flushed . . . every day and then [the] dressing changed and cap changed every week . . . So I do her line care, and I give her chemo and her antibiotics, just bathing her too is difficult because you have to put a bag on her chest so it doesn’t get wet, her CVL doesn’t get wet.

27: It crippled him, he couldn’t walk, he couldn’t move his arms, I couldn’t touch him still. It was so hard to bathe him, he’d just scream and he’d be in pain, all I had to lift him around the house.

Other tasks involved maintaining their home by doing household chores such as grocery shopping, laundry, cleaning and cooking, and meeting the day-to-day needs of other their children such as getting them to school and ensuring they were clothed and fed.

21: Her brother at first missed a lot of school, and he was very worried about her. He thought his sister might die and it was very hard. Children of single parents generally have abandonment issues anyway and so for him as a sibling of someone who has, of another child who has cancer, it was very difficult. So, my role was parenting both children. And I didn’t want to separate them too much and act as though her brother didn’t have a lot of needs as well because he did.

Living conditions

Single parents were balancing the emotional, informational and physical caregiving tasks under pre-existing stressful living conditions. Our findings revealed that many of the single parents were living under financial strain, and some were experiencing geographic and housing instability (e.g. fear of eviction, moving residences etc.) that were part of their lives before and after the diagnosis of childhood cancer.

Financial strain

The majority of parents in our study described their financial circumstances as dire. As many of the parents in our sample did not have large financial savings prior to the diagnosis, when they had to stop working to care for their sick child, they described a marked financial change. A few parents were on the verge of declaring bankruptcy, some reported an inability to provide for basic needs such as being able to afford food and clothing, resulting in accessing food from food banks, a few had their utilities cut off, and some were using their savings to pay for day-to-day expenses. Parents also relied heavily on Government support such as Employment Insurance and Welfare and on not-for-profit/charitable organizations like food banks, and hospital resources for the basic day-to-day necessities. Participants described their experiences as follows:

1: I went to employment insurance sick benefit. I went a couple of months without an income. Though this income is like half of what I would normally get, so I have to make some big financial adjustments to make that work for me. Being a single parent I never had a heck of a lot of money to start with so now to have that cut in half is definitely going to be very stressful. And it’s only going to last until January and then she is still going to be in treatment so I still have to deal with that after this, so, I think that part is hard, it’s if anything I would love to see somebody recognize that a single parent caring for a child needs to be home and be supported.

26: It’s bad because when I don’t have the money and I know I only have ten dollars and I don’t eat three meals a day I’ll just go to Burger King and I’ll just buy the five dollar meal, and I’ll just think ’okay that’s my breakfast, lunch and dinner.’ Because I don’t have money to buy food every day so . . . . The money situation is the lowest point I think because there’s been days that I haven’t ate at all because I just don’t have money to eat.

Geographic and housing instability

Some single parents described feeling fearful of losing their home, or being unable to pay rent. As paediatric cancer care is
highly specialized, some parents had to uproot and move themselves and their families to be closer to the hospital. Others had to move into more suitable living conditions for their ill child. A few parents described recent moves that had happened just prior to the diagnosis of childhood cancer. These geographical shifts had negative impacts on families, as siblings had to change schools, or in some cases, be separated from their sole parent when it was not possible to accommodate the whole family in the new living situation. Moreover, because of lower socio-economic status of some of the parents, the neighbourhoods they were living in were sometimes removed from the downtown core where the majority of the hospitals were situated, meaning long commutes for parents, especially for those who did not own cars.

27: I’m so broke, my car is just about to fall apart, I’m about to lose a wheel and I’m behind in my rent six hundred dollars they’ve given me an N4 for eviction again, I just got it because I didn’t pay for September all of it yet. . . . I’m trying to catch up but it’s so hard.

21: In order for her to come home from her bone marrow transplant we had to move to a different home, and we did, but the new one, I had to change the flooring because they had carpets, they had black mold and stuff. We had to have all that taken out and laminate flooring put down and a few other things too. So it cost a great deal.

Overall physical and mental health

Single parents’ overall physical and mental health was compromised as a result of their caregiving duties. Our findings revealed that parents experienced both mental and physical health problems prior to, and during their child’s diagnosis. Here we outline some of the overall findings about parent’s general overall health during and prior to their child’s diagnosis that were part of the day-to-day stresses they were managing while caregiving.

Mental and physical health

Caring for a child with cancer had a marked health impact on parents including a range of physiological and psychological symptoms. Many parents described disturbances related to sleep, diet and exercise habits, and reported instances of anxiety, depression, and generally feeling down while their child was on active treatment and/or in the recovery stage (see Klassen et al., in press). Importantly, parents in our study reported experiencing a range of pre-existing health conditions before their child was diagnosed with cancer. Some had accessed psychological counselling services for other problems in the past, and some were on medications such as antidepressants for several years prior to their child’s diagnosis. Moreover, some reported having a personal injury or illness such as diabetes, hypertension, hepatitis C, thyroid problems, obesity, and back problems.

12: I’ve had some thyroid issues that started sort of way back, I became hypothyroid . . . my doctor put me on Synthroid medication, now a lot of these symptoms, fatigue and aches are symptoms of that as well as [clinical] depression.

22: I was already on antidepressants ’cause I have depression. . . . Yeah I’ve been on them for over like ten years.

Family histories

A surprising finding in this study was the discovery of family histories that included disruption and trauma. While we did not directly ask questions about the pre-treatment family trajectory, these findings arose spontaneously in the single parents’ narratives about their lives leading up to their child’s diagnosis.

History of family disruption

Some single parents in our study described turbulent histories of family disruption prior to their child’s cancer diagnosis. As would be expected with this single-parent population, the majority of the parents were either divorced or separated and some had a history of more than one break-up. A few families had contact with social services including foster care, and/or police intervention with their own children. Some single mothers reported a history of physically and emotionally abusive relationships with their ex-partners. One example of an abusive relationship was described as:

13: I think this is an advantage for me to be a single parent now . . . Because, you know, at least he’s [ex-husband] not there to abuse me anymore. . . . He’s not there to teach this really bad behavior to my children.

In some instances, parents described alcohol and drug abuse in the other partner as instigating the break-up. Some mothers also talked about their ex-partners incarceration, and a history of unstable partners. The uncertainty and unpredictability of the involvement of their ex-partner in their children’s lives resulted in high stress levels for these parents.
You were asking about the relationship with the father, if they’re out of the picture or if they’re in the picture. It was a little bit more stressful for me not knowing. I think if they were a part of their life then that’s one thing, and if they’re not a part of their life that’s one thing, but for me that inconsistency, that not knowing was more stressful for me.

Their father’s really not that involved with the children ‘cause like he’s in and out of jail and stuff and like he’s just not, his lifestyle doesn’t entail children.

As is illustrated in the above quotes, some parents described positive aspects of being single even if it was because of family disruption. In addition to preferring more predictable living situations that did not involve an ex-partner coming and going, parents also talked about being able to focus on entirely on their child’s needs without worrying about the demands of their stressful ex-partners. For example, one parent explained:

He was a drinker so not having to deal with that whole aspect of it . . . so just not having that burden on you, another burden on you on top of being with somebody that you really know you shouldn’t be with. That was a huge relief when we finally went our separate ways, a huge sigh of relief as horrible as that sounds. You set your own schedule, you don’t have to worry about other people’s work, you can do what, and when you want . . . For me that was that would be the biggest thing, I would rather be a single parent even with all the struggles and stresses than I found it way more stressful in different ways.

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History of family trauma and disease

In addition to family histories of disruption, we also found that some of these families had a history of trauma and disease. A few parents experienced death of their spouse at a relatively young age from heart disease, suicide, murder, or other fatal diseases. One mother described her experience as follows:

After my husband died like I had a lot of trouble eating, like I think just like the anxiety and like the grief. I just felt so sick for such a long time. So then I was getting a bit better and then when she got diagnosed, it just kind of went back. I was just so stressed out.

Some parents also described losing their own parent(s) at a young age, as well as experiencing the death of a close family member within the past 5 years including the death of a grandparent, sibling or a friend often from a terminal illness such as cancer.

Discussion

The primary objectives of this study were to understand how single parents of children with cancer describe their experiences of caregiving and to understand the challenges that single parents may experience because of issues associated with being a single parent. Single parents caring for children with cancer were burdened with several cumulative stressors including a history of abuse, living with financial strain, having instances of loss of family members because of a range of causes including murder and fatal diseases, and experiencing stresses associated with caring for a child with cancer including detrimental psychological and physical health outcomes. The synergy of these cumulative stresses with the added strain of caregiving for a child with cancer may have long-term health and financial implications for parents. When the findings of this study are understood within a cumulative stresses framework, it is possible to see the complex relationships between the single parents living conditions, family histories of disruption and trauma, and overall mental and physical health. Moreover, it allows us to draw implications for research and policy.

Research on cumulative stresses

Cumulative Stresses is a theoretical model which suggests that negative life events have an enduring and multiplying impact over an individual’s life course (Merton 1968; Dannefer 2003). The idea is that small disadvantages early in life may grow over time and increase burdens on individuals and families (DiPrete & Eirich 2006). There is research to suggest that the more negative events an individual experiences in a given time period, the higher the likelihood they will suffer from more injury, illness, disability, or in some cases, even death (Tennant 1999; Cohen et al. 2007). This ‘pile up’ effect increases the risk of psychological distress and predicts recurrences of psychiatric disorders, mood disorders, post-traumatic stress disorders, and alcohol and substance abuse (Thoits 1995, 2010; Mirowsky & Ross 2003). The social determinants of health that make up cumulative stresses include socio-economic status, quality of housing and nutrition, impact of social exclusion, and discrimination (Duncan et al. 1998; Wilkinson & Marmot 2003). The social determinants of health that make up cumulative stresses include socio-economic status, quality of housing and nutrition, impact of social exclusion, and discrimination (Duncan et al. 1998; Wilkinson & Marmot 2003). These cumulative stresses were salient when examining the landscape of single parents’ lives in our study. In the following discussion, we outline the potential implications of our findings for the single parents in our study.
Implications of cumulative stresses and caregiving

Financial strain and housing and geographic instability

Financial stress was the most pronounced burden that single parents caring for a child with cancer faced. Having a child with cancer meant being a full-time caregiver, and therefore, being unable to work, sometimes for a short while, but often for an extended period of time in the context of an already precarious financial situation. This financial stress may have repercussions for both the children and their primary caregiver at diagnosis, and across the lifespan. Research suggests that some caregivers for ill people are disadvantaged and may never fully recover from the financial, emotional, psychological and physical impact of this ‘time out’ of the workforce (Yun et al. 2005; Goldbeck 2006). Another study that looked at welfare recipients in California where more than half the sample were single parents found that families where children had a disability or a chronic illness were more likely to have unemployed mothers, to incur extra expenses because of child’s illness and more likely to live in deep poverty (Lukemeyer et al. 2000).

The implications of financial strain on health across the lifespan have been robustly documented. Low-income adults have the highest rates of morbidity, disability, mortality, psychological distress and mental disorders compared with those with a higher social-economic status (Hayward et al. 2000; Mirowsky & Ross 2003; House et al. 2005; Wilkinson & Pickett 2009). Moreover, chronic stress and hardships such as poor housing, being unable to meet basic needs, lower social status, being more socially secluded or isolated lead to poorer health outcomes (Wilkinson & Pickett 2009).

While our study focused on the caregivers and did not look at the children or their health, there is some evidence to suggest that parental financial strain can also have an impact on children’s well-being. Canadian children living in low-income families are more likely to experience a variety of illnesses, hospital stays, accidental injuries, mental health problems, poor school achievement and early dropout, family violence, and child abuse (Power 1992; Werner & Smith 1992; Canadian Institute of Child Health 2000). Sick children living in poverty are at an increased risk of adverse health outcomes including higher medical complexity, longer stays in the hospital, missing more hospital appointments, and a greater likelihood of death because of their medical conditions (T. McNeill, unpublished). For childhood cancer patients specifically, there is some research to suggest that low socio-economic status of parents may lead to greater mortality rates (Blakely et al. 2003; Son et al. 2011).

Physical and mental health

Our findings revealed that many single parents experienced a range of physical and mental health problems before the diagnosis of cancer. These findings are corroborated in the literature on single parents’ health and well-being which suggests that single parents are at an increased risk for physical and mental health problems (Franz et al. 2003; Cairney et al. 2004; Crosier et al. 2007). Olsson and Hwang (2001) found that severe depression is more likely for single than married mothers of children with intellectual disabilities. Delle and colleagues (2006) found higher parental stress and more physical health problems for single mothers when compared with married mothers of children with rare diseases.

History of family disruption and history of family trauma and disease

Some single parents in our sample whose children have cancer had family histories of disruption and trauma prior to the diagnosis of cancer. When understood within the cumulative stresses frame, these family histories become significant in understanding the potential additional burden and strain for the caregiving parent. There is evidence to suggest that childhood and adult traumas not only increases individuals experiences of more stressful events and strains but that these strains and traumas together explain more variance in negative mental health outcomes than any individual negative event on its own (Turner et al. 1995; Wheaton 1999).

In addition to predicting greater psychological distress for the adult, disruptive or chaotic family structures (e.g. family conflict, family breakdown, parental desertion) can have an impact on the children (Werner & Smith 1992). For example, change of mother’s partner, or conflict between mother and her partner is associated with mental and physical problems such as anxiety, depression and or behaviour problems in children (Keeping et al. 1989; Najman et al. 1997). Moreover, exposure to interparent violence as was reported in our sample, is associated with suicide attempts in children, higher incidences of being victims of violence themselves, alcohol abuse, anxiety problems, and drug abuse (Fergusson & Lynskey 1997; Fergusson & Horwood 1998).

Implications: broader view of caregiving impact on single parents

In one of the longitudinal studies available on single parents, Avison and colleagues (2007) found that in sample of 518 single
mothers and 502 married mothers, single mothers experienced significantly higher levels of distress because of their greater exposure to chronic stress and strain over time when compared with married mothers. The most pronounced stressors for these single mothers included financial, caregiving, and workload strain and it was the combination of these multiple stressors that caused the distress rather than any one stress on its own. Another study looking at the late psychosocial consequences for parents (married and single) whose children had cancer similarly found that parents who have multiple stressors (e.g. low socio-economic status, chronic disease in another family member etc.) may have more difficulties in coping with the problems inherent in childhood cancer at diagnosis and years after treatment is over (Van Dongen-Melman et al. 1995, p. 583). As with our findings, it appears as if the ‘pile-up’ effect of cumulative stress may be associated with tremendous burden on single parents and that this may become even more salient when facing an acute crisis such as having a child with cancer.

Given the potential psychological and physiological consequences of cumulative stresses on parents and their children at the time of diagnosis and across the lifespan, policy and clinical implications for single parents whose children have cancer might focus on a broader view of the caregiving impact on these parents. Hospital-based interventions might include assistance with some of the caregiving tasks described in the first set of findings including respite care or home care to help with other children in the home, or volunteers who might be able to drive or accompany children to appointments in the hospital. Other resources might focus on facilitating the emotional needs of the whole family through psycho-social care and taking into consideration the unique needs of these single parents given their potentially turbulent histories in addition to the current stressors they are facing. A third intervention could include increasing satellite services or other strategies to get care for their sick child in their home and communities.

Key messages

- This is the first study to report on both the caregiving demands and the contextual life stressors faced by single parents whose children have cancer during and prior to their child’s diagnosis.
- This is the first study to address the unique present and historical life challenges faced by single parents in the context of paediatric oncology.
- Focuses on the potential short and long-term health and financial implications for single parents.

Implications for practice and/or policy:

- Hospital-based interventions should include assistance with caregiving tasks including respite care or home care to help with other children in the home.
- Services should help facilitate the emotional needs of the whole family through psycho-social care and taking into consideration the unique needs of single parents given their potentially turbulent histories.
- Satellite services should be increased in order for parents to get care for their sick child in their home and communities.
- Broad policy interventions should focus on relieving the chronic strains and include: ensuring that parents have adequate, affordable housing, work-time flexibility, and Government paid leave.

Conclusion

More broad-based interventions should focus on relieving the chronic strains associated with being a single parent and might include: ensuring that parents have adequate, affordable housing without fear of eviction, work-time flexibility and Government paid leave to relieve the financial strain while caregiving, and a programme designed to ease single parents back into the workforce after active treatment and home care treatment is over. These short-term interventions that focus on ameliorating the impact of these chronic stresses on parents may lessen the financial burden on the Government and the healthcare system in the long term, and most importantly, ensure that children with cancer and their single-parent caregivers have the resources they need to cope with this crisis and thrive in the aftermath of the event. Further study is necessary to evaluate these potential interventions to gauge their efficacy in alleviating some of the cumulative stresses on single parents caring for a child with cancer.

Conflict of interest

No conflict of interest has been declared by the author(s).

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