Lived experiences of parents caring for a child with a life-limiting condition in Australia: A qualitative study

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Abstract

Background: Experiential studies in paediatric palliative care are needed to enable an ongoing international agenda which supports the development of responsive family supports.

Aim: To provide an in-depth exploration of the prevalent lived experiences of parents who are currently providing care for a child with a life-limiting condition in Australia.

Design: Cross-sectional, prospective, qualitative study guided by an advisory group and reported according to the consolidated criteria for reporting qualitative studies. Transcripts were subjected to a thematic analysis, underpinned by an interpretative phenomenological framework.

Setting/participants: Purposively sampled parents (n=14) recruited from a statewide paediatric hospice who self-identified as a ‘primary caregiver’ for one or more children and/or adolescents (<18 years) with a life-limiting condition.

Results: Four key themes represented the prevalent experiences of parents: (1) trapped inside the house, (2) the protector, (3) living with the shadow and (4) travelling a different pathway. They describe parents’ physical and social isolation, exclusion from the workforce, pervasive grief and associated impacts to their health and well-being. Limited professional and diminished social supports resulted in full ownership of care responsibility. Yet, parents embraced their role as ‘protector’, reporting acquired meaning and purpose.

Conclusion: This study builds upon the growing body of evidence available in paediatric palliative care internationally. The key themes highlight the substantial demand for both physical and emotional support beyond what is currently offered and call for the implementation of carefully planned support services and other societal initiatives which seek to alleviate the broad health impacts to caregivers.

Keywords
Paediatric palliative care, life-limiting condition, qualitative, caregiver, experiences

What is already known about the topic?
- Family caregivers of children with a life-limiting illness are required to tend to a diverse range of complex healthcare needs for an extended length of time and face significant psychosocial challenges.
- There is a lack of studies in Australia and internationally which provide specific insights into parental experiences when faced with issues pertinent to paediatric palliative care services.

What this paper adds?
- This study demonstrates the substantial demand for both physical and emotional support beyond what is currently offered by existing paediatric palliative care services.
- Caregivers are unable to easily participate in a majority of current support options, given life as a caregiver is largely contained to the home.

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Introduction

Paediatric palliative care is an emerging subspecialty focused on providing holistic and integrated care across the illness trajectory to enhance the quality of life of children and adolescents with a life-limiting condition. Support for the young person’s family is a central component of this approach. Paediatric life-limiting conditions have been characterised into four disease archetypes with varying morbidity, although they share the commonality of probable shortened lifespan with possible or certain early death.

Recent UK data suggest an increasing incidence of paediatric life-limiting conditions, affecting 32 in 10,000 young people aged from 0 to 19 years. Improved medical care, ongoing dependency and disability are common for those living with such conditions. Thus, there is a growing population of caregivers who are required to tend to their child’s diverse and complex healthcare needs for an extended time. The significant psychosocial challenges faced by these caregivers are well recognised. Parents report clinical levels of distress, moderate fatigue and below-average quality of life. Such impacts may also persist into bereavement, leading to the increased overall mortality rate of parents after the death of their child.

Studies internationally have focused on parental coping and adjustment, supportive and palliative care needs and perceptions of services. There is a paucity of qualitative literature exploring the lived experiences of parents and limited focus outside oncology, where increased supports may positively influence experiences. This included usual considerations such as seeking consent to audio-record, outlining subsequent use of data, highlighting participants’ right to cease the interview at any time, take their time or skip questions and assurance of confidentiality. Additionally, if parents were particularly distressed, the interviewer offered to

Implications for practice, theory or policy

- More readily available and consistent in-home psychological support, grief counselling and respite services are warranted alongside out-of-home options to enable caregivers improved access to supports.
- With a growing population of caregivers, there is a need for a considered and innovative caregiver workforce strategy which assists caregivers to re-train in roles that can utilise the new skills acquired during caregiving or provide mandated support for flexible working arrangements.
facilitate further support options through a hospice family support worker, community psychologist or general practitioner.

Participants

Participants were parents who identified as the ‘primary caregiver’ for one or more children/adolescents (≤18 years) diagnosed with a life-limiting condition. A letter of invitation was sent to all English-speaking, non-bereaved families registered with Victoria’s sole paediatric hospice. All parents who volunteered to participate in the study were asked on the survey (Phase 1) to indicate their interest for potential participation in an interview (Phase 2) to explore their experiences in greater depth. Those interested were then categorised and purposively sampled to ensure representation on a series of variables: length of time caring, child’s disease and health status, Association for Children’s Palliative Care (ACT)/Royal College of Paediatrics and Child Health (RCPCH) disease archetype,² distance from hospice and geographical region. The selected sample was phoned to arrange a time and location convenient to them.

Data collection

Semi-structured face-to-face interviews of 45- to 120-min duration were conducted between September 2013 and March 2014 by one researcher (A.C.) with experience interviewing palliative populations. The interviewer was independent to usual support staff known to participating parents. Interviews were held in the parent’s preferred location (home, n = 13; hospice, n = 1). Although permitted, no couples (i.e. two parents from one family) indicated their interest to participate.

In line with the exploratory aims, parents were invited to provide narrative account of their caregiving role. Prompts were used to explore areas of interest not spontaneously covered, including key challenges and rewards associated with caregiving and perceptions of available supports and services. Flexibility in the interview schedule was maintained to allow the interviewer to follow new lines of enquiry or clarify emerging themes.

All interviews were audio-recorded, transcribed verbatim by an independent transcription service and checked for accuracy by the interviewer (A.C.). Data collection was undertaken simultaneously with analysis and ceased at saturation, when no new perspectives were being introduced by participants.

Data analysis

An inductive, concurrent, thematic analysis³⁰ underpinned by an interpretative phenomenological framework²⁹ was conducted by two independent investigators (A.C., N.H.-A.). This framework was selected to provide a rich overall description of caregivers’ experiences as they perceive them to occur in their everyday life, while accurately reflecting the entire dataset. The analysis process involved several distinct phases as described by Braun and Clarke:³⁰ immersion in data by repeated, active reading and production of initial codes that identify a feature of the data; interpretation and sorting of codes into potential sub-themes or categories; refinement of themes, including at the level of the coded data; and consolidation of overall thematic map (including a third independent investigator: K.T.), ensuring accurate and clear reflection of the meaning of the dataset as a whole.

Results

Participants

Of the 145 parents who participated in the broader study, 62 parents (43%) volunteered for potential inclusion in the current sub-study. Of these, 14 parents (12 mothers and 2 fathers) were purposively sampled for interview (Figure 1). Included parents were of a median age of 40 years (range: 25–51 years) and had been providing care for their child for a median of 7 years (range: 0.5 months–18 years). The families were regionally representative and lived in a median of 42 km (range: 12–168 km) from the hospice. They were mostly Australian-born (n = 12, 86%), with the remaining two parents from Vietnam and Macedonia. Eight parents (57%) were partnered, while six were separated or no longer living with their partner. One parent was caring for two children with life-limiting conditions.
Few parents ($n=4, 29\%$) had remained in their current employment setting since becoming a caregiver. The majority ($n=10, 71\%$) had stopped work ($n=4$), reduced their working hours and/or changed career path to accommodate more flexible work options ($n=6$).

The median age of the children being cared for by the participants was 10 years (range: 3 months–17 years). They had a range of diagnoses which represented the four ACT/RCPCH disease archetypes\(^2\) (Table 1). The child’s family had been registered with the family support services at the paediatric hospice for a median of 2.7 years (range: 6 months–12.5 years).

### Key caregiver experiences

Four key themes represented the prevalent experiences of parents caring for a child with a life-limiting condition: (1) trapped inside the house, (2) the protector, (3) living with the shadow and (4) travelling a different pathway.

#### Trapped inside the house

The experience of feeling ‘trapped inside the house’ describes parents’ physical and social isolation from community, their exclusion from the workforce and the associated impacts on their health and well-being that resulted from accepting the role of primary caregiver.

The hardest part is I want to be part of the community.

(C02)

Some days I feel like I’m trapped inside the house. Getting out at all … it’s difficult. (C06)

Parents reported difficulties attending everyday ‘normal’ activities outside of the home as their child’s fragile or unpredictable physical condition often precluded their participation. Their ability to travel was restricted given unsuitable accommodation and transport facilities which can cater to the child’s needs:

Isolation is the biggest thing. Like I can’t you just put him in the car, lie him down and take him places. (C01)

We’re not game to go out anymore because you never know when a seizure is going to hit. (C05)

#### Seclusion from community

Parents also perceived their child was often excluded from typical social occasions (e.g. parties, sporting games) due to their poor health. In turn, they too missed out these activities which would afford them the opportunity to connect with other families:

We’re quite limited in what we can do – so you find you don’t get invited. (C12)

It would be nice for him to do a Saturday morning sport like other kids do … I know he can’t but that means we miss out on the whole social thing too. (C01)

Overtime, their ongoing restricted ability to participate, high stress and need for support led some parents to report feeling they were a burden to others. Some expressed actively withdrawing from friendships owing to their seclusion and desire not to ‘burden’ friends:

I don’t like to hassle or call my girlfriends more than once a month, because I haven’t got anything good to say. When you

### Table 1. Characteristics of children being cared for by included participants.

<table>
<thead>
<tr>
<th>ACT/RCPCH Archetype I ($n=3$)</th>
<th>Metastatic pleomorphic xanthoastrocytoma ($n=1$)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life-threatening conditions for which curative treatment may be possible, but can fail</td>
<td>Leukaemia ($n=2$)</td>
</tr>
<tr>
<td>ACT/RCPCH Archetype II ($n=3$)</td>
<td>Central congenital hyperventilation syndrome ($n=1$)</td>
</tr>
<tr>
<td>Conditions with long periods of intensive, life-prolonging treatment and expected premature death</td>
<td>Multicystic bilateral renal dysplasia ($n=1$)</td>
</tr>
<tr>
<td>ACT/RCPCH Archetype III ($n=5$)</td>
<td>Cystic fibrosis ($n=1$)</td>
</tr>
<tr>
<td>Progressive conditions without curative treatment options, where treatment is exclusively palliative</td>
<td>Schwartz-Jampel syndrome ($n=1$)</td>
</tr>
<tr>
<td></td>
<td>Sandhoff disease ($n=1$)</td>
</tr>
<tr>
<td></td>
<td>Degenerative neurological condition ($n=1$)</td>
</tr>
<tr>
<td></td>
<td>Nemaline rod myopathy ($n=1$)</td>
</tr>
<tr>
<td></td>
<td>Lennox GAST syndrome ($n=1$)</td>
</tr>
<tr>
<td></td>
<td>Severe cerebral palsy and associated complications ($n=2$)</td>
</tr>
<tr>
<td></td>
<td>Serious undiagnosed neurological disability ($n=1$)</td>
</tr>
</tbody>
</table>

ACT: Association for Children’s Palliative Care; RCPCH: Royal College of Paediatrics and Child Health.
have a child like this, it’s amazing how many people aren’t your friend. (C05)

Exclusion from workforce. Parents described how caring demands restricted them from carrying out former vocational aspirations. Some were forced to give up work to care for their child, while others changed to voluntary or casual roles that enabled more flexible working hours. Committing to regular hours was considered impossible by most, incompatible with their need to be available and drop everything when required:

I can’t even work part-time because I have to be able to drop everything when the phone rings. (C05)

I’ve never been able to get a permanent job …. It’s the ‘what if’ factor that you’ll need to give it all up … it’s just better not to take certain things on. (C13)

Parents reported their sense of loss from giving up work and expressed a desire to return to the workplace, although they felt unsupported to do so. Exclusion from workforce was construed as lost opportunities to participate in the community, engage in adult conversations and maintain a sense of self:

I’ve had to give up work to care for her. I hate it because it was the only thing for me. You know, I was me, I wasn’t mum …. Losing that was huge. (C12)

I can only commit to a few hours a week … so I’m just doing some voluntary work to get me out of the house. (C06)

I don’t want to be defined by being a carer. (C02)

Inability to prioritise own health and well-being. Parents described the physical and emotional impacts to their well-being associated with the caregiving role. Persistent extraordinary stress and provision of 24/7 care led to significant fatigue and impacted carers’ emotional health:

There’s an ongoing cost, and it’s both the physical cost, and the emotional cost. (C14)

I feel quite alone and overwhelmed with this caring role that seems like a life sentence, or solitary confinement. (C01)

Impacts to physical health (e.g. chronic back pain) were also reported from the ongoing demands involved with providing care (e.g. lifting):

Just caring for him and the seizures, I think the stress brought everything to a head and I had a heart attack. (C03)

I don’t sleep properly, I don’t eat properly. And when I get stressed I lose weight. (C05)

Despite the significant toll to their own health, parents felt unable to tend to their own health needs or physically attend their own healthcare appointments as caring responsibilities were constant and always prioritised:

When you’ve got someone else in the family that’s unwell, you do end up putting yourself last. We can’t do what we need to look ourselves. (C13)

I probably need continued therapy to help me cope but I just can’t make it to the appointments. (C03)

The protector. Parents described the enormity of their caregiving role, conceptualised as being ‘the protector’ of their child. This role as ‘protector’ entailed holding all knowledge of the child’s unique and specific care needs and also all ownership of the responsibility associated with caring duties.

Full knowledge of care needs. Parents described an intimate knowledge of their child’s care needs, which were perceived to be nuanced, unique and different. Given the rarity of many of the life-limiting conditions, parents felt others could not fully understand their child’s needs or ways of communicating. This included family and friends, as well as professional carers:

It’s so hard to send him somewhere with a list of instructions when there’s so much I know about him … I can’t necessarily put that on paper. (C03)

It [the breathing mask] can’t be too tight, or it gives him sores. It can’t be too loose, or it won’t work …. And the machine has to be lower than him too. It is basic stuff but you have to get it right. I’m the only one who knows. (C10)

Full knowledge of the child’s condition and associated care needs was considered essential to be able to respond immediately in times of emergency, which were largely unpredictable and rapidly changeable. Specific knowledge of how to manage complex disease-related symptoms or sequelae such as seizures, dialysis, peg feeding and suctioning meant usual social supports were not useful:

Our families have been apprehensive about helping because of his epilepsy. You know, ‘If he has a seizure, what are we going to do?’ (C05)

Only I know the ‘emergency exits’. Every time she vomits I have to know is it the medication? Is she sick? Do I take her to the doctor? Do I not? These are just things that other normal people don’t know how to deal with. (C02)

Full ownership of responsibility. Parents described how they chose to take on full ownership of care tasks in an effort to minimise impacts to the child and other family members. Recognising the demands of the caring role and
the impact to their own physical health, parents expressed how they could not expect others (e.g. parents or friends) to fulfill the same duties:

The harsh reality is he’s heavy and awkward to lift. It’s one thing for me to put my back out, but I can’t expect others to do it. (C03)

I’ve tried to make sure that [my other children] don’t have too much responsibility for her. I don’t want them to feel resentful. (C07)

There’s no nurse to administer medication at school, so I’ve got to sit here [at school] for her to attend. It’s been a long gruelling term of doing nothing, but that’s what you’ve got to do. (C12)

Parents described difficulties teaching others the knowledge required to provide ‘best care’, and thus felt unable to have a break without compromising the child’s standard of care. As ‘protector’, the prospect of their child receiving suboptimal care in order to have a break was considered unacceptable and associated with a significant emotional burden (e.g. anxiety, guilt). Additionally, in the absence of one ‘go-to’ service which could meet all of the child’s needs, parents had limited confidence in giving over responsibility for their child’s care, instead assuming all responsibility to act as full-time carer, advocate and coordinator of care:

I know I need a break, but going to the beach without him is such a mixed emotion. There’s this sense of guilt you’ve palmed him off. (C03)

Sometimes I wonder if getting a break is really worth it. I know going to respite upsets him and I could just keep going. (C08)

This is my burden, and only mine. (C05)

Living with the shadow. This theme describes the pervasiveness of living with the probability of the child’s death. For all parents, the idea of death was mostly unspeakable. Uncertainty and grief for the life that could have been were common, both for themselves and for their child and family.

Navigating the uncertain future. Chronic uncertainty relating to a child’s prognosis was expressed through a preoccupation with survival statistics and possible time-frames given by differing medical professionals:

In Australia, 600–700 people will die waiting for a kidney transplant. But, does that include the people who aren’t active on the list? This stuff is always in the back of your mind. (C07)

I don’t know how much time I’ve got left with my little girl. (C12)

Many parents actively chose to focus on the present, given an unknown or daunting future. This fear of the future persisted even when the child’s condition was stable because knowledge of increasing care needs as the child ages or, worse, the potential for another crisis remained:

It’s the ‘what if’ factor … the future of not knowing. It’s better to live in the now. (C13)

It’s doesn’t just switch off because you survive a milestone. No one’s ever said he’s out of the woods. So it’s not really ended. (C14)

I don’t like to think about [the future] because it’s not going to be good. I think it’s just going to get harder. (C01)

There is just no straight answer, no one has a crystal ball, no one can tell us. (C05)

An unspeakable end to the child’s suffering. Parents facing a more imminent, certain trajectory spoke of ‘waiting’ for their child to deteriorate. When pertinent, the eventuality of death or sometimes the poor quality of life of the child was mostly unspeakable. However, for some parents, death was conceptualised as an inevitable relief associated with an end to their child’s suffering:

She’s OK with feeding at the moment, but we know that that will go. We’re waiting for that to happen. (C02)

She has a progressive disease …. So yeah, we’re expecting her to die within the next two years. (C07)

To be honest, palliative care for us is almost a relief – knowing that maybe one day soon, he will … I’m just saying it’s a horrible life for the poor kid. If someone could just tell me it will end. (C01)

All parents reported feelings of helplessness and abandonment, knowing death was inevitable, albeit unspeakable:

It’s cruel. I look at her every night and say, ‘I wish I had a magic wand’. I wish I could do something. But the doctors are at the end of the road. They don’t know what to do with her. So if something happens, what’s the point of calling an ambulance? That’s when it hits, there’s no one. (C05)

I think we learnt early on it’s a wait and see. So it’s pretty hard putting him down for a sleep and every time worrying, you know, if I would go back in there and find him gone or not. (C03)

It [death] could happen anytime … that’s what’s hard …. And it’s not in my power to stop it. (C08)
Grief for what could have been. For all parents, grief for the life that could have been was common, both for themselves and for their child and family. There was grief for the child, because they were deteriorating, regressing or were forever changed:

We have grieved our child. It sounds horrible, but he’s not the child we had. That child’s gone. (C01)

She was such a bright bubbly thing, and now there’s nothing. Every now and again you see bits. (C11)

November was a grieving month for us. We knew that we’d lost the girl we had. (C07)

There was also anticipatory grief over their possible, or more certain, impending loss of a child. Finally, parents described grief for personal losses, associated with an inability to live life as they had imagined:

I’m constantly grieving. Like when we’re out in the garden and I wish he could pull on his gumboots and run around with us and climb trees. (C03)

She is 13 now. I could have reasonably expected that she’d be able to let herself in after school. But she can’t. (C02)

Travelling a different pathway. Parents spoke about the way in which their life just happened to go in a different direction to that of others, revealing how they both conceptualised and acquired meaning and purpose from being a caregiver.

Deriving meaning through adversity. Parents described how their caregiving role generated a changed perspective, involving a new capacity to see what is important. They described an inner resiliency from surviving ongoing adversity and hardship. Losses to their earlier self and relationships were consoled by this new capacity to see what is meaningful in life:

She’s given me the capacity to see things differently. (C02)

You feel as though you live in this different world of ‘big issues’, almost like an outsider, you feel completely different. (C13)

She’s taught me I can cope. I can get through …. It’s made me a stronger person. (C05)

Despite this valued perspective, some parents expressed an ongoing hope or belief that supports from health services will be improved in future to enable them to live out personal goals, such as returning to work:

My goal is to get back to work three days a week. I have to believe that’s possible. (C02)

Living a new life course. Parents accepted that taking on the caregiving role meant embarking on a new life path. Their life as a caregiver was described to be ‘different’ to the one they had imagined or expected, but the finality of their circumstances was conceptualised as part of life’s new course for them:

I was on a corporate trajectory, flying around, selling equipment. She changed my direction. (C02)

This is obviously part of my journey and I just have to go with it. (C05)

It’s just you change and you try to find a new pathway that’s right for you. (C13)

For some, the caregiver experience led them to develop a new community of supports that understood the challenges, embraced disability or who are travelling a similar path. Parents reported this new life course involved ‘giving back’, by sharing their knowledge to support others also on this different path. They also spoke of a new purpose to engage the wider community in issues pertaining to disability and advancing illness:

I’ve never felt like I’ve belonged to a group like I do with the amazing people I’ve met because of his disability. I feel like I have something to give now -someone can benefit from what I’ve been through and that feels good for me. (C03)

We need to engage the wider community so they understand. (C02)

Discussion

This study is among the first to detail parent perspectives of caring for a child with a life-limiting illness in Australia. The experiences described by participants provide rich and nuanced insights into what it means to be a primary caregiver in this setting and, as such, have relevance to the few studies conducted internationally. Despite developing a changed, valued perspective of what is meaningful in life, the significant isolation and exclusion from community and workforce as a result of accepting the caregiver role was profound. Such experiences raise important considerations for improvement in supports, with implications for both service- and policy-level initiatives. The results suggest a mismatch between services offered, current standards of care and recognition of caregivers’ difficulty or sometimes inability to utilise supports outside the home.

Consistent with research from the United Kingdom and Canada, caregivers qualitatively reported the many years of providing care (in this sample, median of 7 years) impacted their own emotional and physical health. Although recognising this impact, caregivers were unable to prioritise their own needs while necessarily continuing
to provide care. Specific challenges raised here resonate with some earlier themes reported internationally, including the need to become the ultimate expert in the child’s care, attempts to preserve aspects of normality within family life, the synonymous battle with both the child’s disease process and the health system and, most poignantly, the numerous evolving losses.

To date, there is limited prospective research available to understand the long-term health outcomes for this group. One population study from Denmark with an 18-year follow-up after bereavement showed an increased mortality from both natural and unnatural causes in mothers and an early increased mortality from unnatural causes in fathers. The experiences described by caregivers in this study echo this demonstrated need to develop more effective supports. Simultaneous research focus is also needed to investigate whether increased supports can prevent such long-term morbidity.

**Implications for service initiatives**

While a full commentary on possible service improvements is outside the scope of this study, the experiences shared by caregivers point to some important service considerations. As they are currently offered, caregivers are unable to easily participate in support options. Although the experience of isolation would suggest increasing hospice-based supports may serve to decrease caregivers’ emotional seclusion, the physical isolation facing carers also restricted their ability to engage in this type of support. Caregiver life was largely contained to the home, where it was perceived that the child’s needs could be best supported. Thus, more readily available in-home psychological, counselling and respite services are warranted alongside out-of-home options, to enable caregivers improved access to supports.

Out-of-home respite is one interventional strategy which has demonstrated benefit for parents of children with life-limiting illness in the shorter term. Longitudinal follow-up would be helpful to evaluate whether it continues to be useful for those parents able to access it on an ongoing basis. In addition, other models of in-home respite provision should also be investigated to both increase access and assess potential benefits derived. In particular, the role of trained volunteers who could provide support options in the home could be highly acceptable to parents and should be explored in greater detail in future.

An expansion of in-home grief counselling services is also warranted to assist caregivers to cope better with the ongoing losses and uncertainty described. While expressing a need, most parents were not in a position to attend repeated counselling sessions out of the home. Additionally, in the setting of diminished friendships and social networks for a majority of parents, a peer mentoring or online ‘buddy’ service which was adequately resourced and facilitated by professionals may help to build community and reduce isolation felt by parents. Sharing their unique expertise developed through caregiving with others may additionally enable parents to derive ongoing meaning through their experience.

**Implications for other policy initiatives**

In this study, caregivers described a lack of current workforce options which could accommodate their needs for flexible working arrangements. As a result, caregivers reported feeling excluded from their earlier career aspirations, with the majority having to give up work to provide care or change to a role which allowed more flexible options. This finding is consistent with earlier data on parental employment, suggesting up to 88% of parents suffer work disruptions and 49% cease employment to provide care. However, this study highlighted that workforce issues are significant beyond financial hardships encountered. For some caregivers, employment changes were equated with a loss of self. In response, parents sometimes sought out voluntary roles as a professional caregiver to provide themselves with another purpose and to maintain some connection with life outside the home. While bereaved carers were not included here, future studies should seek to explore the potential difficulties associated with the transition back to the workforce after becoming a full-time caregiver.

With a large population of current or bereaved lay caregivers globally, and a demonstrated simultaneous need for in-home support options, there are opportunities created which could capitalise on the acquired skills and perspectives developed while living as the caregiver of a child with a life-limiting illness. Introducing a considered and innovative national workforce strategy which assists caregivers to re-train in roles that can also utilise the new skills acquired during caregiving may be of benefit. This would involve identifying roles in the community where these skills are transferrable, such as serving as advocates for other parents, acting as support group leaders, providing education to the wider community or acting as disability aides in schools. Likewise, mandating flexible workplace options for caregivers placed in this situation may enable some people to remain in their chosen profession. In any case, this would require further work including bereaved caregiver perspectives, to consider at what timeframe after the death of a child, a parent may be able to re-engage with the workforce or, if desired, assist other parents of children with life-limiting illness.

**Limitations**

This study has several limitations. As a descriptive qualitative study, the sample size was small. Despite sharing the common ground of facing a child’s probable death and the
chronicity of caregiving, there will likely be some variation in experience across included disease archetypes, although small numbers limit our ability to draw detailed conclusions. In addition, despite being open to both parents, the sample comprised mostly mothers, given very few fathers self-identified as the primary caregiver. Although this may be broadly representative of parental caregiving arrangements, it would be advantageous to understand the unique challenges facing fathers who do undertake the role or who necessarily remain in employment given family financial strain.

Finally, having recruited parents who were registered with a statewide family support service, we are unable to comment on the experience of those who either chose not to be linked to this support or who have not been made aware of the service. Likewise, although two parents from minority cultural backgrounds able to speak sufficient English were interviewed, we have not been able to capture a broad representation from differing cultural, non-English speaking or indigenous backgrounds. These groups may have different perspectives and experiences of the caregiving role and deserve full attention in a future study.

Conclusion

This study builds upon the growing body of evidence available in paediatric palliative care and provides close insights into the lived experiences of parents who provide care for their child with a life-limiting condition. Although parents embraced their caregiving role, reporting acquired meaning and purpose, the key themes highlight the substantial demand for both physical and emotional support beyond that which can be provided by extended family and friendship networks, or even beyond the scope of current paediatric palliative care service provision in the community. While much focus is placed on the clinical care needs of children with life-threatening conditions, future work will need to consider the implementation of carefully planned support services and other societal initiatives which recognise and seek to alleviate the broad health impacts to caregivers in this setting.

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