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Two Futures: Financial and Practical Realities for Parents of Living With a Life Limited Child

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ABSTRACT

Today more and more children are living with complex health care needs, many of these children are living with life limiting and/or threatening conditions, some are medically fragile. To live a childhood these children must live in communities and with their families. In most cases this means the child's carers, their parents, most often their mothers, are required to undertake a great deal of the child's care. During a project on parental coping I became aware of the ways in which parents were restructuring their working lives in order to meet the demands of the nursing and medical care needs of their children. In this paper I relate the stories we discovered in this qualitative study and discuss the tensions between parental and state's responsibility for children, carers and the political and cultural rights and responsibilities pertaining to children's care. I use Margret Urban Walker's ideas of expressive collaborative morality to argue that the care of life limited and life threatened children should be framed in a negotiation between the state and the carers, both informal and professional. That such an agreement should include a covenant to assist parents and siblings when a child dies to recover and adjust to their loss, in recognition of the work they have performed in caring for the child during their child's life and their death.

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Introduction: Care, costs, and consolations

In this article I consider a subsection of the data from a qualitative study undertaken on three sites in the south of England. The method and findings of this study will be reported elsewhere; here I focus on an incidental finding which, even after more than two decades of nursing practice, shocked me. In our study we did not set out to investigate the parental view of financial and practical aspects of the care of children with life limiting/threatening conditions, but this was an incidental finding to our findings on parental coping. I start this paper by setting out some of the complexity of the context of life limiting/threatening conditions in childhood. I briefly review the limited literature on financial aspects of parental caring for this group of children.

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There is a brief description of the main study before I set out the themes of the data relating to the financial and practical issues of parental care. These are then discussed in particular with reference to Margret Urban Walker's feminist moral understanding (Walker, 2007). I have previously discussed the use of this negotiated approach in *Pragmatic Children's Nursing* and provided worked examples (Randall, 2016). I conclude by making recommendations for a covenant between the state and parents of children with a life limiting/threatening condition.

To begin, it has been documented that technical advances and a change in social attitudes have led to more children living with life limiting conditions outside hospital settings (Fraser et al., 2011; Glendinning, Kirk, Guliffrida, & Lawton, 2001; Lewis & Lenehan, 2012). Although we know that the numbers of these children are growing, defining this population and their nursing need is complex (Brook & Hain, 2008; Grinyer, 2012). A way to visualise this complexity is to imagine a volcanic island. At the rim of the volcano there are children who are in our world, as molten lava or ephemeral volcanic ash, but who then are gone. This group might include children born with conditions not compatible with life, who live for a short period. In the terms of Shaw et al. (2014) Spectrum of Children's Palliative care needs, these children might be in the red category. As one travels down the volcano's slopes the lava becomes more solid, a childhood is lived, but with the threat of a pyroclastic flow. These are conditions where death may occur in childhood, for Shaw et al. (2014) these are orange and yellow categories. Towards the ocean there is a lagoon, if we think of the ocean around the island as the population with a normal life expectancy, then the lagoon feels like the wide ocean, but there are rocks dividing these children from the ocean. So these are life threatening conditions in which we might see the child moving toward normal life expectancy, but which have challenges that may again curtail the child or young adult's life. These children would be in the green category of the Spectrum. Just as the structure of a volcanic island is unpredictable and subject to violent changes, so the childhoods of these children and the lives of their carers are overshadowed by a dual reality of both living with a condition and the possibility of death in childhood.

In addition to the uncertainty of the lives of children living with life limiting/threatening conditions is the increasing technical devices and interventions that assist in children's lives (Carnevale 2007; Feudtner et al., 2005). These new technical opportunities and the realization that children are active social actors in their childhoods has led to an increase in the delivery of complex nursing care in a variety of settings outside the traditional hospital areas. It is now normal practice for children with tracheostomies and even those who require ventilator mechanical support, and or, who have oxygen supplementation to use these technologies at home, at school, and in the street or supermarket (Carnevale 2007). Our view of childhood and of illness and disability in childhood now includes understanding how important it is for children to live a childhood which as far as possible is similar to that of their peers in their communities (Randall, 2016).

The shift of care from hospital to community settings has increased the care requirements of parents and of the child's informal carers. While there are examples of professional nursing services supporting and supplementing parental care (Neilson, Kai, McArthur, & Greenfield, 2013; Tuffery, Finlay, & Lewis, 2007) in the main the care needs of children living with life limiting/threatening conditions and disability are met by their informal carers. This responsibility falls, unequally, on mothers, but it also impacts fathers, siblings and other family members. State governments recognize the responsibility of parents (Guardians), including the responsibility to meet healthcare needs of children (Department of Children, Schools and Families, 2009; Department of Health, 2000). However, states also recognize their duty to their young citizens (UN 1989; UNICEF 2013) and the role of the state in ensuring children can access healthcare, which includes the access to palliative and end of life care (WHO 2014).

What emerges here is a complex picture of children who may be considered disabled, or who have complex healthcare needs, and who may or may not be considered to be life limited/threatened, but whose informal carers (mothers) are managing much of the nursing, social, and educational care. The death of one's child is considered one of the most terrible things that can happen to a human. The psychological and social costs are well described (Bluebond-Langner, Belasco, Goldman, & Belasco, 2007; Grinyer, 2012) albeit that death and dying remain taboo subjects in many culture and especially so in childhood. However, the financial costs and practical implications of a child's death are not so well understood. Corden, Sloper, and Sainsbury (2002) conducted a small qualitative study that found household income fell, and while parents were aware that benefits would stop after 8 weeks, the speed of the income loss shocked them and added to their sense of loss. In Dussel et al.'s (2011) survey of parents bereaved by the loss of a child to cancer, 16% of American parents and 22% of Australian parents fell below the poverty line. These studies have focused on income after the death of the child, rather than considering implications for housing and employment both during the child's life and in bereavement.

Two futures: Parents' work and caring

During a qualitative study we undertook of parental coping, a number of stories began to emerge about the financial and employment situation that parents of life limited/threatened children found themselves in. Understanding the employment and financial situation of parents was not the purpose of our study, rather this data was uncovered as we progressed with the study. The findings of the study will be reported elsewhere, but suffice to say here we conducted 24 semi-structured parental interviews relating to 20 children. The majority were bereaved parents (21) but 3 parents lived with a child with a life limiting condition. The parents were recruited from two large urban pediatric intensive care units and one children's hospice. The interviews were conducted by two researchers separately, and included face to face, telephone, and Skype interviews. The study had the required ethical approval, and informed consent was gained from all participants; interviews were audio recorded and transcribed verbatim. The transcripts were analyzed separately by two of the research team and agreed by the team. Nvivo software was used to organize the data and a thematic analysis was undertaken (Silverman, 2003). Out of our sample, employment and financial concerns were raised in interviews relating to 13 children of whom 10 had died (2 were neonates when they died) and 3 remain alive. The parent participants included 10 women, 6 men, and 4 couples who were interviewed together. As might be expected some aspects of financial and practical arrangements affected some parents more than others. Some participants mentioned all three themes detailed below some only one.

Restructuring work and living arrangements

Parents told us how they had restructured their working lives to accommodate caring for their child. One father re-trained and became a self-employed tradesman in order to have more flexibility to care for his child. Other families moved to access local special schools or to be closer to extended family members who could help with care delivery. Some parents attempted to continue working, and some had no choice, but being employed outside the home and caring for a seriously ill and or disabled child seemed very onerous, if not impossible.

> (She) was very poorly in the April/May time, I was working, I was with her when it happened but she had a big crash they had to resuscitate her which … she was very, very poorly and then I think the stress just got to me because I was working three long days, I was up in the night with her most the time, she wasn't sleeping very well, she would be crying in the night mainly because we realized that she kept waking herself up because she couldn't breathe, she had sleep apnea quite badly and so in the end I said right well it's time to kind of walk away from work for a while, so I gave up in December and so I've been at home since then. (Female Participant 16)

Couples and men recognized that the role men filled in going out to work and securing an income, had both negative aspects and positive ones.

> Female Participant 17: … think that's an indication of, I don't know men have perhaps got a so called 9am – 5pm job to hide behind.
> Interviewer: I'm glad you used those words.

> Male Participant 17: I think I'd have, I've used it as a focus.
>
> Female Participant 17: What, work? But that's a good thing isn't it? Isn't that a positive side to it, it's a coping, well OK a good side of that is also that it's a coping mechanism and it gives you a way of coming out of the all consuming thing of looking after [named child] and looking after the family and it gives you the ability to come back in and bring something fresh. (Couple Participants 17)

In some cases, men and women reported employers being flexible and for one bereaved father this flexibility gave him time to be with his child, which in retrospect he was thankful for. The working lives and other living arrangements for these families are then overwhelmingly affected by the child living with life limiting and serious illness and disability. When a child dies these restructured living and employment arrangements are again disrupted.

Dying costs: "We've not even just lost a child, we've lost a whole way of life"

Parents in our study reported both the anxiety about what will happen when their child dies and the reality of the distress and financial hardship suffered at the time of the child's death.

> There isn't an end date on anybody's life but equally we have to prepare for two futures. We lose the house, we lose the car very quickly and that's the reason we've got our own dog and not a working dog from someone else because if the dog was under eight we'd have to give it back and I don't think the other two would cope very well with losing the house, the car, the dog, and their sister at the same time, so that's why the dog is our dog. We need to stay in this area so we are now having to move, we need our benefits etc. but we also need to be saving money because actually we will lose everything but the child allowance, everything will go very, very quickly. I'll need to go back to work quite quickly and that's the reason I took on the chairman role because I was thinking about our two futures because if I had been out of management for that amount of time then how am I going to get a job? (Female Participant 16)

This family had moved to be close to family, there were siblings who were in local schools. This move into local authority accommodation was only possible because of the child's disability. Once the child dies the family were told they would have to give up their house for another disabled person, despite the property being modified for their child. The family car was leased under the Motability scheme as they required a large adapted vehicle for their child's wheel chair and equipment, this too would have to be returned on the child's death. Other families experienced similar disruption and financial hardship on the death of their child. A different family who were in receipt of a substantial financial settlement in a case of medical negligence, which was settled out of court, not only had their funding withdrawn immediately, but had to repay the balance of the annual settlement as the child died in the first few months of the year. This family were having to sell the family home, and also move sibling's schools as they could not afford the mortgage on the property without the child's care payments, nor could they afford another property in the same area. These issues appeared then to affect parents from different socioeconomic backgrounds. However, those who had given up paid employment to care for their child seemed hardest hit

> I was getting obviously disability living allowance, carers allowance, all of that and I suddenly went from that to well I lost about 90% of my money but still had every outgoing. … having to have money worry as well as grieving was a real joy. Didn't appreciate that at all and then council tax, bedroom tax, they then charged me for the room that my son was in, so there were some really horrible things to deal with after which I really could have done without, they kind of push you over the edge a little bit.
>
> Yes, just because I had to keep getting signed off because obviously the minute my son died I lost all my income; mum and dad fed me for the first year I had no money at all, that was it, any money I'd had I'd used on the funeral so I was literally just my whole life had completely fell through the floor basically. (Female Participant 2)

Returning to work, to life

The process of dealing with financial/employment and living arrangements and bereavement seemed to be overwhelming for the parents we spoke to. The immediate problems of notifying various bureaucracies of the child's death was a process that many found difficult, isolating, and confusing.

> I had to ring, I remember the child tax credit people, I rang them up, and the guy had to put the phone down because I was crying, it upset him, he said I'm really sorry, I'll have to take a moment. And I think how the bloody hell do you think I feel. There's nobody trained, you know, you can't say, there's this one telephone number because you've been bereaved, and this one telephone number lets all the relevant people know. I had to go in to each one … it's almost like you want one person initially to say, I'm really sorry to have to let you know, but this is the practical side of it, would you like us to make that phone call, and it's almost like you want somebody else to do it, you know, or one number that takes care of everything, because it's soul destroying having to go through. You're in bits like this, and having to explain it, and you're making other people feel awkward, it's horrible, horrible. But that was the overriding memory of after she went, is just how alone really I felt. (Female Participant 12)

Parents talked about the longer term effects of bereavement on their ability to work. This included being unable to work and needing to be deemed unable to work by their family doctor, as well as the difficulties of returning to employment. The challenges of returning to the work place sat alongside those for people who had been out of paid employment for some time and who felt deskilled, particularly those who had previously been in career orientated employment.

> I never had a job for 14 years because I was looking after my son so it's not if I have a job to go back to already I probably would be back doing that now but when you are having to start over completely and again with my son's needs and my needs now in a completely fairly unique situation I haven't got a husband, I haven't got another child to focus on, haven't got a job to go back to I've got to basically restart and moving forward is actually the hardest thing. (Female Participant 2)

> . . .so she was in customer care and they moved her out of that one when she went back after her 30 week(s) because she didn't really want to deal with someone who had lost their cake voucher! As I've said to my wife before, I said on that day, that's what's important for that person, they haven't gone through what we've gone through, they might not have any hardship in their life, but we have, but they don't know that! So they are bothered by a cake voucher, people just wanted some cake. (Male participant 18)

Discussion

As I listened to these parents what struck me was that these people were doing what we might expect, their lives changed when a child came along. As parents all our lives are changed by children. These children demand more of their parents, but with love and help from their friends and families the parents rose to that challenge. They adapted their work and careers to the new situation of caring for a child with complex healthcare needs. They willingly took on the care of these children, care which, if they as parents did not deliver would have to be delivered by the state, by professional nursing services. Often the parents provide this care over many years and by doing so substantially reduce the financial cost to the state, to communities. The uncertain prognosis combines with the changing physical, emotional, and psychological demands of providing care to these children who live with two futures, one where the child lives with nursing and medical needs, and the other where the child dies, and parents, siblings and other carers of the child have to re adjust to the loss of the child, and return to paid employment, (re) adapt their lives again.

The picture here of rights and responsibilities either accepted or rejected/ reassigned is what was described by Margret Urban Walker (2007) in her work on feminist moral understandings. I have argued elsewhere that Walker's expressive collaborative morality is applicable to children's nursing (Randall, 2016). In this case rather than a judicial theoretical morality, where an official judgement draws on ethical principles, we see responsibilities and rights being negotiated between the parties. Concerns and issues are expressed, either in public, or more often in private (in family and friend networks, to trusted nurses), responsibilities for the upholding of rights are either accepted or rejected, or rather mostly they are avoided or placed elsewhere. The parties collaborate both in the acceptance of responsibilities and in the rejection/reassignment of them. Typically (but not exclusively) as we can see above, mothers accept the responsibility for ensuring children access their right to healthcare, fathers avoid their responsibility by a claim to earning an income for the family (a claim which may be accepted by women and supported, or resented, and or rejected). Nurses are also either accepting responsibility for care (often technically complex care) which they frame as professional care, and which tend to be overshadowed by the aspects of nursing which support the practice of medicine. Administration of medication, or technically complex care such as tracheostomy and or mechanical ventilation. Or they reassign this work to parents (Glendinning et al., 2001; Kirk, Glendinning, & Callery, 2005). The work described here of care of the carers, and bereavement work, including employment, financial advice, and liaison with local housing and social care, is all work which is not so well recognized as being a part of nursing (Randall, 2010, 2016). Arguably this aspect of nursing fits with Liaschenko's (1997) conception of nursing as a boarder practice, in that nurses are working across the borders of the various interests, professions, and agencies, as well as the borders of what a society assigns as the responsibilities of parents of children living with illness and disability and the responsibilities assigned to professional nurses. Liaschenko (1997) highlighted the potential risk of "spacial vulnerabilities" which in this case may be further complicated by the stigma of disability, dying, and death in childhood, such that these negotiations on collaborative working remain private, hidden, or not expressed at all. As the data presented here suggest, the responsibility for supporting bereaved parents may not be recognized and accepted by nurses, or any other health or social care worker, and parents can feel that they are left isolated, shouldering the responsibility alone.

What seemed to be against all natural justice is that parents should receive so little support when their child dies. When they have saved the state years of care costs, not to receive some grace on housing, to have their car removed, to have their care payments removed, in effect to be expected to be back to work in less than a few months, is cruel and uncivilized. Surely a civil society would honor a covenant of care, in recognition of the service and financial burden parents have undertaken in caring for their child and their loss, the state should provide a coordinated, comprehensive package of care and support to bereaved parents.

A covenant of care package should, based on what parents have told us, include an allocated key worker to coordinate informing relevant governmental and other education, social, and healthcare organizations; a legally enforceable moratorium on changing housing, transport, financial, and other arrangements relating to the deceased child's care for 6 months, and; a package of employment help and support for parents to re-enter paid employment. Such a covenant would not just provide for the bereaved it would also bring some certainty for those living with two futures, providing care for a life limited/threatened child. If parents could know that they and their surviving children would have time to adjust, that someone will help them in bereavement to rebuild their lives (as much as they can), then they could prepare themselves for both futures. The covenant would apply before the child dies, thus employment training could be provided to maintain employment skills and funding provided for networking opportunities. A communication plan for when the child dies could be included in advanced care plans, already in widespread use.

This was an incidental finding in a qualitative study. We did not set out to explore financial and other living arrangements. The fact that it emerged in the data from 13 interviews conducted by two interviewers separately is perhaps indicative of the strength of parental concern. However, to understand if this is a widespread challenge and the specific nature of the phenomena would require a more detailed qualitative study followed by a population survey.

To be clear, I am not suggesting a more masculine theoretical judicial approach, where legislation would be stipulated and enforced, but rather that nurses embrace Walker's expressive collaborative approach: That being aware of the negotiated collaborations, these agreements to accept responsibilities and deliver access to rights are expressed and made explicit, transparent, and public.

Declaration of interest

The author reports no conflicts of interest.

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