Caring for a young adult with cancer: the impact on mothers’ health

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Abstract
That the carers of people with cancer are profoundly affected by their caring role is well established, yet the needs of one particular cohort, i.e. the parents of young adults with cancer, have not been well understood. The majority of carers in this situation are mothers, and it is the impact of the emotional and physical labour entailed by the care of young adults that is the focus of the present paper. Through the analysis of qualitative narrative data contributed by the mothers of young adults with cancer, the aim of this paper is to examine the health effects for women of caring for a young adult son or daughter with a life-threatening illness. The results suggest that there is an impact on the mother’s health that results in unspecific, low-grade and chronic psychological and somatic symptoms which the mothers rank as a low priority. The mothers’ attempts to appear to be managing may serve to mask their own health needs from health professionals whose primary concern is the health of the son or daughter. Where psychological distress is admitted, the resulting use of prescribed antidepressants may not be experienced as helpful. The conclusions are that, because of the particular circumstances of caring for a young adult son or daughter with cancer, health professionals’ attention to the mothers’ health throughout the cancer journey may act as a preventative measure for later and more serious ill health.

Keywords: cancer, caring, health, mothers, young adults

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Introduction
The National Institute for Clinical Excellence guidelines (NICE) (2005) for children’s and young people’s cancer services focus predominantly on the needs of the young people who are ill, and this is quite appropriate; however, the guidelines also recognise that there is a psychosocial impact on families and carers. Recognising the importance of the effect on the wider family, the focus of the present paper is to understand better the implications for the health of the mothers of young adults (18–25 years) with cancer who are also their primary carers. Because the sons and daughters in such a situation have a life-threatening illness, attention to health issues understandably tends to focus on the young person with the acute illness rather than on her or his carer, usually the mother. However, the potentially life-threatening illness of a son or daughter contributes to a unique set of circumstances that is likely to have a profound effect on their emotional and physical health.

The meaning of illness is fluid and categorised into ‘normal’ illnesses (e.g. colds and flu), ‘real’ illnesses which are life-threatening, and ‘health problems’, which are not classed as illnesses as such, but are related to processes perceived as natural (e.g. ageing, the menopause, reproduction and mental health problems, including depression and anxiety) (Miles 1991, p. 42). Such differentiation may be of relevance when interpreting mothers’ reporting of their own health issues in relation to the ‘real’ illnesses of their sons and daughters.

Thankfully, cancer is relatively rare in young adulthood. Birch et al. (2003, p. 2622) reported national incidence rates in young people aged 12–14, 15–19 and 20–24 years to be 10.1, 14.4 and 22.6 per 1 000 000 population, respectively, with lymphoma and leukaemias being the most frequently found cancers in the age group

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covered in the present paper. We can see that the incidence rises during the teenage years and early twenties; nevertheless, the numbers are still low at only 0.5% of all cancers in 1999. However, the very rarity of the illness in this age group may add to feelings of isolation and distress experienced by a son or daughter who has been unfortunate enough to be one of the few who develop it.

Women as carers

That it is women who are the primary carers of elderly and sick people comes as no surprise. As Lee (1998) argued, this situation is regarded as ‘normal, natural and unalterable’ (p. 110). The emotional labour of caring for the sick child, in addition to the tasks of managing the household, allows us to define this labour within the domestic sphere as ‘real work’ (Morgan 1996). However, the result of these efforts is, according to Read (2000), that the family is kept going, but the equilibrium is fragile, and the toll on the health of the mother, both physical and emotional, can be far-reaching.

Maher & Green (2002) documented the fact that the majority of people caring for at least 20 h per week said that their health was affected by caring, but that support services such as visits from health visitors and other social services were more likely when the carer was not living with the person they cared for. According to Payne et al. (2004), it also seems that informal carers are not recognised as being in need of support themselves. This not only leaves them with the burden of care and limited support, but no acknowledgement of their own health needs by professionals who might be able to access support services on their behalf. It has been suggested that a cheerful disposition is regarded as crucial to the caring role (Lloyd 1999). However, the gap between how carers feel and how they appear may have implications for their mental health given the exhaustion and depression that they experience as a result of the lack of support afforded to the role of the unpaid carer. Hirst’s (2004) study of care givers endorsed these findings, and while he said that carers are more likely to exhibit emotional and mental health problems than physical health problems, he also acknowledged that carers may not have the time or energy to look after their own health needs. Many of the symptoms experienced may be regarded as unspecific, chronic and low-grade, and women experiencing them may ‘work through’ them in a way which more acute or life-threatening conditions would preclude. As Popay (1992) claimed, if a symptom is ‘common’, it is more likely to be considered ‘normal’ and not defined as an illness.

There may be a tacit assumption that care is most likely to be given to the elderly and infirm – usually a parent or parent in law of the female care giver – but as Hirst (2004) argued, providing care for elderly people or those with disabilities does not automatically result in psychological distress. Such distress is more likely to occur when caring for a sick child or one with disabilities.

However, the mothers in the present study were the primary carers not only for a son or daughter, but a young adult son or daughter with a life-threatening illness – cancer – thus adding an additional layer of emotional distress and possibly increased physical demands. There is a strong cultural assumption in Western society that our children should outlive us. As Milo (1997) observed, the death of a child at any age runs against the natural order. It is also the case that the resulting impact on family dynamics when a young adult is forced into dependency on those who cared for her or him in infancy can be experienced as challenging and result in an exacerbation of the situation (Grinyer 2002a).

Subjects and methods

The data which form the basis of the present paper have been collected from the mothers of a young adult son or daughter with cancer. The mothers were responding to an appeal for information about their own health after having originally participated in research about the life-stage issues relating to the diagnosis of cancer in young adulthood and how this, in turn, impacted on them as parents.

The original appeal was made by Helen, the mother of a young man called George who had died at the age of 23 years after a 4-year battle with osteosarcoma. During George’s illness, his family had struggled with managing difficulties which they believed were related specifically to George’s age and life stage; however, they found little published work from which to draw support or information. As a result, after George’s death, his parents set up a charitable trust to support research in this area so that the life-stage effects and the resultant impact on the family might be better understood.

The original approach to parents had been made via cancer and palliative care networks. This resulted in the parents of 28 young adults with cancer (predominantly mothers) from a wide range of professional, educational and class backgrounds contributing written narratives. This method for the collection of qualitative data, as discussed by Harris (2002) and used by Thomas (1998, 1999a, b) to gather data in similarly sensitive areas, was thought to be the most appropriate way to approach parents. Using the narrative correspondence method ensures that participants remain in control of the process, and that they can pick up or put down their account as and when they feel strong enough to recall events which are likely to engage with distressing memories. It also relieves them of the pressure of having to respond.
to an interviewer at a prearranged time, which may be experienced as intrusive or to have occurred at a 'bad' time for them (Grinyer 2002a). The resulting data were contributed in a variety of forms, handwritten, word-processed or e-mailed. They varied in length and reflected a range of skills with the written form. However, what all had in common was a richness and depth that allowed a rare insight into the most private and painful events of family life. The content of many of the narratives is so intense that it seems unlikely that an interview would have elicited the same information. Indeed, some of the accounts were written not specifically for the research, but were in the form of contemporaneous journals which documented the cancer journey in great detail, articulating the despair experienced. In a follow-up study (Grinyer 2004a) after the publication of a book based on the accounts, the participants expressed a gratitude in 'legitimating' narratives which had remained forgotten, sometimes for years, while others wrote of the therapeutic nature of the writing experience and the 'permission' they had been afforded via the research to express their thoughts in such a way. The follow-up study also made apparent the fact that many parents viewed the outcomes of the research (a book and other publications) as a 'lasting memorial' to their lost son or daughter that acted as both a tribute and a tangible record.

The original data set raised a number of key issues relating to the life stage of young adulthood in relation to life-threatening illness. These issues tended to correspond to the research 'question', which was on the impact on the family as a whole, and where health was addressed by the participants, it predictably focused on the health of the son or daughter. Nevertheless, embedded within the original narratives written by the mothers were implicit indications that their own health had been compromised. After returning to the data and extracting information on this theme, it seemed worth approaching the mothers to ask them to contribute to the research again – if they felt able – by addressing their own health needs during and after the illness of their son or daughter. The follow-up study had indicated which participants would be willing to contribute further, and thus, it was with a degree of confidence that these original contributors were again approached. Some parents had indicated that, while they had valued their participation, they wished to move on at this point and would not care to contribute to further research; these parents were not contacted. This resulted in 13 requests for information on mothers' health and the submission of nine accounts. Clearly, such a small sample cannot claim to be representative, and it needs to be acknowledged that the contributors were also self-selected. Nevertheless, it seems that the quality of the data, coupled with the similarity of experience, suggests that the issues raised are still of importance when considering how professionals can best offer support to families undergoing such an experience.

Throughout the research project, ethical issues were fundamental to the design and implementation of the methods. However, the research was not carried out with patients and it was not situated in a medical setting, and thus, an approach to a Multi-Site Research Ethics Committee (MREC) or a Local Research Ethics Committee was not deemed appropriate. At the point when the research was instigated, i.e. 1999, the institutional ethics committees which abound at the current time had not yet been established, and there appeared to be no mechanism for ethical consent to be granted. As a member of the British Sociological Association, the present author is bound by their code of ethical practice; nevertheless, it did seem prudent for the research design to gain approval from a body outside the research team and this was given by the board of the charitable trust set up after George's death. At the time, the board consisted of members with a wide range of experience and professional expertise, including a barrister, a Macmillan nurse, a medical social worker, two academics and an National Health Service (NHS)-based complementary therapist. The standards and rigour, both ethical and methodological, have stood up to the scrutiny of peer review in a range of publications based on the research (Grinyer 2002a,b, 2004a,b, 2005, in press a, in press b, Grinyer & Thomas 2001, 2004). The second phase of the research, begun in 2005, has received approval from a university ethics committee and an MREC, and also from Research Governance at local NHS trust levels, and the present author’s extensive experience of the newly established departmental ethics committees in universities suggests that, had such a process been in place at the time, approval for the first phase would also have been granted.

It is crucial that transparency and rigour are demonstrated in the analysis of qualitative data if they are to avoid being dismissed as ‘merely anecdotal’ or highly selective. Mindful of such a requirement, the data were rigorously analysed using methods of data reduction, display and conclusion drawing (Miles & Huberman 1994). Miles & Huberman (1994) noted that extended text is dispersed, poorly structured and extremely bulky, and that, in order to avoid jumping to unfounded conclusions, or over-weighting a particularly dramatic passage, certain processes must be observed during analysis. To this end, the data have been subjected to codification. They have been sorted and sifted in a manner that facilitates the identification of similar phrases, themes and patterns. Through the identification of commonalities and differences, and a consideration of the relationship between the variables, a set of generalisations...
was gradually developed to cover the consistencies discerned in the database. The headings below reflect these themes, and although they are overlapping and interconnected, arising as they do from material that is unstructured, there has been an attempt to organise them into a coherent structure that allows a degree of analysis, even though the original words of participants can be so powerful that it can be tempting to allow them to speak for themselves.

Results

Feelings of isolation

As expected, and endorsed by the literature discussed above (Traustadottir 1991, Williams 2002), women (mothers) were the primary carers in both physical and emotional terms. As a result, they could find their social world closing in on them by becoming confined to the home. This social isolation (Read 2000) was experienced as oppressive by some of the mothers, yet they still interpreted their role as of lesser importance in contrast with the status of their husbands’ uninterrupted employment.

One mother, Anne, who had needed to give up work before her daughter’s illness because of her own pre-existing ill health, said that she felt guilty that her husband was still having to cope with a demanding job while, as she said: ‘[A]ll I do is stay at home.’

Yet staying at home was not necessarily the easy option since it was the mothers who provided both the intimate physical care – sometimes heavy and demanding and distressing – and the emotional labour, perhaps staying up though the night to talk to their son or daughter as Helen did with George, while still having the household to run and other children to support. The social isolation was accompanied in many instances by the continuing and sometimes competing needs of the rest of the household (Read 2000).

The differential emotional engagement between husband and wife also created a divide that could result in tension and leave the mother feeling isolated even within the family structure. There were many indications in the original narratives that the mothers needed to engage emotionally and talk about the illness and their fears, while the fathers discussed the situation in much more practical and pragmatic terms, refusing to address their own anxieties or those of their wives. While only two of the marriages failed as a result of the illness, many others were put under severe strain. This strain also took its toll on the emotional health of the mothers in a way that was not always apparent to others – including the husbands – having far-reaching implications for the carers’ mental health (Lloyd 1999).

The absorption of low-grade ill health

Anne, whose pre-existing health problems had been diagnosed as myalgic encephalomyelitis (ME) and Addison’s disease, experienced many non-specific, but debilitating symptoms which she managed without input from health professionals. The tendency to absorb low-grade ill health, whether emotional or physical, is further illustrated by Sue, whose son Paul died. When she was asked by a friend if she had suffered with depression during the menopause, said:

How could I measure my own feelings about myself when Paul was ill? Perhaps analysis by a professional would have judged me emotionally disturbed but on the outside I think I presented a controlled front most of the time.

However, Sue ‘kept going’, and after Paul’s death, cared for her sick mother and also her daughter, who developed cancer herself. As Sue said – she didn’t have the time to be ill and to the outside world it must have seemed as though she was coping – what choice did she have? But after her mother and Paul had both died, her daughter had recovered, and she was no longer caring for anyone, her blood pressure ‘went crazy’ and she started having chest pains. She had a year off work, had counselling – and cried for 3 months. She commented: ‘This was the worst thing I had ever experienced.’ She subsequently took ill-health retirement from her job as a deputy head teacher. This example illustrates well the gap between how a carer feels and how she appears, the strain subsequently resulting in emotional collapse (Lloyd 1999). Yet when emotional needs are articulated and professional help is sought, the outcome may not be experienced as helpful.

Some mothers spoke of their need to take antidepressants with a degree of ambivalence. As Moira said:

At first I fought manfully onward but gave in about 18 months after Alasdair’s death and went for counselling and started on antidepressants. I am only now starting to come off them five and a half years after his death. I was ashamed to be on them but soon learned to accept it was the only way to cope.

A number of the mothers demonstrated similar reluctance. Candy, the mother of Sianne who died, said that, throughout Sianne’s illness and treatment, she can only say that she ‘lived on her nerves’, and that since that time she has never been able to relax and is in a constant state of anxiety. Although she says she copes ‘day to day’, she cannot look forward to anything or feel happy. While Candy had taken antidepressants several times, she had always stopped taking them because she ‘didn’t like the idea of them’ and felt that they only masked the symptoms. But she continues by saying:

However, in autumn last year I sunk really low again and I knew I needed some help so I agreed to go back on antidepressants.
and stick it for at least six months. I’m still on them. I don’t know how much they’re helping. I’m calmer than I was ... but the depression and insomnia are still there.

Despite the emotional demands of caring on the mothers, the effects were ranked as a low priority and not distinguished with the status of ‘proper’ ill health, thus contrasting with the ‘real’ illnesses (Miles 1991) of their son or daughter. The women were experiencing ‘normal’ ill health, and this resulted in some reluctance to seek medical advice. The depression or anxiety experienced by the mothers in such circumstances was reactive and situational. They recognised that the numbing of their feelings might make daily life slightly more endurable, but such a coping strategy could not mitigate the reality of the life-threatening illness of their son or daughter.

The interface between emotional and physical ill health

The boundary between emotional and physical health is blurred, and to some extent, artificial. The two may be linked causally, but they are difficult to separate and identify both for the mothers and the health professionals involved in their care. George’s mother, Helen, said that she was aware that her health was seriously compromised during the last few weeks of George’s life, but that her only concern had been that she might not be able to keep going until his death.

After George’s death, Helen sought no medical help for several months, believing that her ill health must be the result of severe emotional and physical stress and would resolve ‘in due course’. When a friend with some medical knowledge suggested that thyroid deficiency might be a problem, Helen said that she was amazed when the general practitioner (GP) blood tests came back ‘off the scale’. She commented that:

It never occurred to me that I might have a treatable physical illness, I simply believed that all my symptoms were due to prolonged stress. However with hindsight I am convinced that four years of acute and relentless anxiety adversely affected my endocrine system and led directly to a situation where I produced almost no natural thyroxin … Without prompting from a friend I could have continued to neglect my own health to a dangerous degree.

Sally, whose daughter Halina died, also addressed the difficulty of establishing a link between the stress caused by her daughter’s illness and death, and her own physical ill health:

It’s difficult to distinguish between the effects of grief and the physical effects of long-term health problems, but I think there certainly are effects. However making definite and direct causal relationships is not something that can be done with any degree of certainty – if at all … A year or so later I was having terrific headaches – bad enough to get worried … It turned out to be Essential Hypertension … Whether this would have appeared at that particular point in time anyway, is anybody’s guess, but it DID happen within 18 months of Halina’s death, so …

Moira, whose son Alasdair died, said that she had all sort of minor infections, such as frequent sinus problems, which kept her off work, but through which she would ‘normally’ have kept going … The doctor told her that it was her immune system reacting to the trauma of Alasdair’s illness and death – as she said: ‘They used to call it dying of a broken heart.’ Charlotte, whose son Sean died, also experienced a range of health problems:

Since his [Sean’s] death I have had stress related severe acne. I cover it up with make up when necessary … My concentration was poor after his death. I got hit by a bus thinking I was in a pedestrian zone and not a bus lane … Some of my health problems were aggravated by being hit by [the] bus, that being caused by Sean’s illness and death.

In this case, we can see that some aspects of Charlotte’s ill health were caused by an accident, but the accident is, in her estimation, a direct result of the mental state she was in at the time. This suggests that the emotional and physical effects can be linked in yet another way: if fatigue and depression result in a lack of concentration (Charmaz 1997), then accidental injury becomes more likely.

Anne had been ill before her daughter Ruth was diagnosed with cancer, so she was already struggling with ill health. However, once Ruth’s very serious condition was diagnosed, not only was Anne’s ill health exacerbated, she felt that there was ‘no space for her to be ill’. Her inclination was to put her health needs second. She said that she tried to hide her failing health from Ruth, and there was a real tension between the chronic condition she struggled with and her daughter’s fight for her life. She also said she couldn’t be the mother she wanted to be. Although she was persuaded by her GP that her own health also needed to be attended to, her agreement was reluctant.

At times, Anne said she was near collapse and was persuaded to attend counselling sessions; previously she would have thought such a need to be ‘a sign of weakness’. It took the counsellor 9 months to persuade Anne to agree to massage therapy since Anne said that she felt that this would not only be self-indulgent, it would also take another hour out of the week – time she should have been spending with Ruth. In fact, the massage therapy proved immensely beneficial. But even now, knowing the benefits, she still would not have taken that ‘time out’ earlier in the course of Ruth’s illness since she held the view that her own health came second.
Emotional ill health may be a common manifestation of the stress associated with caring, but physical illness may also result, although, if it is not directly identifiable as a consequence (e.g. back strain from lifting or other related injuries), it may be difficult to establish a causal relationship. Nevertheless, the tendency we have seen amongst the mothers to neglect their own health needs is likely to result in any (even unrelated) health problem being diagnosed, and thus, treated at a later, and possibly more serious, stage.

Of course, the health effects on the mothers are not over once the illness of their son or daughter is past – whatever the outcome. Anne said that, in the year after Ruth’s remission, the enormity of the situation hit her, and she had a severe ME relapse and was housebound for 6 months.

The lack of attention to their own health problems and feelings of guilt when they can no longer be ignored is, in some cases, accompanied by apparent indifference to the prospect of even life-threatening illness. The conflict with the imperative of her son Mat’s needs is discussed by Iris:

I felt physically sick, and at one stage I was admitted to hospital with suspected appendicitis – I felt in constant pain but didn’t know why. I knew that I wasn’t really ill but seemed to be locked into this black hole of despair … Physically I was constantly exhausted, unable to focus on anything but Mat and his illness: generally worn down.

Iris continued by saying that, during the 2-year period of Mat’s remission, her own physical health improved. However, after Mat’s relapse with a tumour that crushed his lung and squashed his heart, she tried to stay cheerful for Mat’s sake, but concluded that, if Mat was going to die, she would die with him because she felt so wretched.

The following quote from Sally, whose daughter Halina died more than 15 years earlier, demonstrates a number of important issues:

Yesterday I was diagnosed with diabetes which didn’t impress me in the least. I actually fell about laughing when my GP gave me the results – she was so upset about it and couldn’t see what was so funny. (In the middle of the night and today I can’t either!) I told her that there were worse things than insulin resistant diabetes and told her about Halina and her best friend who’s just been diagnosed with inoperable c. of pancreas. She then stopped thinking I was engaging in inappropriate behaviour!

Sally’s ‘inappropriate’ response to this diagnosis echoes Iris and Helen’s lack of concern over their own health and survival. Sally’s response also resonates with Anne’s feeling of guilt at the contrast between her own chronic ill health and Ruth’s need to face life-threatening illness. It is as though the mothers’ health, already low on their agenda, becomes of almost no concern.

Discussion
It is clear from the data that the burden of emotional and physical care fell on the mothers. However, of crucial importance is not simply the ‘care burden’, but the significance of who they were caring for and the devastating nature of the potential for loss. That it was the mothers who shouldered the burden of care does not come as a surprise (Qureshi & Simons 1987, Lee 1998). What may be more surprising is that, having taken on the caring role, this was perceived as, in some senses, ‘the easy option’, in contrast to the husbands’ continued or increased participation in paid work, despite the social isolation coupled with the continuing and competing demands of other family members (Read 2000).

However, the role of carer was accepted willingly in all cases, indeed it seems that the term ‘burden’ is inappropriate when caring for a son or daughter – as Sevenhuijsen (1998) said, care can be a rewarding experience rather than a duty. Nevertheless, there is compelling evidence that the mothers experienced both emotional and physical ill health and the two manifestations could frequently be difficult to diagnose and distinguish. When coupled with the apparent lack of awareness of service providers that informal carers also have health needs (Payne et al. 2004), the problem is compounded. Indeed, none of the women’s accounts suggest that any of the service providers involved in the care of their sons and daughters recognised the health needs of the mothers, despite manifestations of chronic illness.

While it is impossible to establish a causal relationship between their own physical ill health and their son or daughter’s illness, and all it demanded of them, it seems that the two are inextricably linked. In many cases, the difficulty of diagnosis was related to the interconnectedness of emotional and physical pain (Bendelow & Williams 1998), and also to the non-specific nature of their low-grade, chronic ill health, which led to the mothers ignoring their own health problems. This is a finding supported by Popay (1992), who suggested that women dismiss common symptoms as not qualifying as ‘illness’, thus ignoring them or incorporating them into their lives. This tendency could also be exacerbated by the ‘real’ illnesses of the young adults (Miles 1991), making the likelihood of seeking help even more remote. This may particularly be the case when the symptoms are mental or emotional.

When medical help was eventually sought by the mothers, there was a readiness to treat antidepressants not experienced as helpful by some of the women who were resistant to such intervention, as Miles (1991, p. 192) argued; psychotropic drugs are seldom of unmitigated benefit to those who use them. The above author also suggested that, as there is no diagnosis called
'unhappiness', doctors have a tendency to use the catch-all medical categories of depression, anxiety or neurosis. Therefore, it seems that the mothers were being pathologised for what could be claimed as a rational response to an unacceptable situation – the life-threatening illness, and thus, the possible loss of a son or daughter. Nevertheless, if there is a shared assumption that a ‘genuinely’ sick person is physically ill, and that it is questionable whether depression should be regarded as an illness (Miles 1991, p. 43), the mothers may not have perceived themselves as ‘ill’ in the first place, again contrasting with the ‘real’ (i.e. physical) illness of their sons and daughters.

While medical advances have meant that cancer may be an increasingly survivable illness, advances in social care have not kept pace; indeed, as Cardy (2005) wrote, the gap between health and social care remains largely unaddressed. In the case of young adults who are predominantly cared for in their family of origin by their mothers, the concept of social care can be stretched to encompass not only the individual with the illness, but also those who take on the responsibility for care. The danger is that the health of the mother is rendered invisible by the imperative of the acute and life-threatening illness experienced by the son or daughter.

Conclusion
That the families of cancer patients have psychosocial needs is reflected in policy documents (Department of Health 2000, Australian Senate Community Affairs Committee 2005). We can also see that the needs may extend beyond the psychosocial and relate to physical health. Nevertheless, as Watson et al. (2004) asserted, there are concerns that the current understanding of the stresses and sacrifices demanded by care giving are not adequately addressed. Indeed, Payne et al. (2004) suggested that caregivers are not always provided with appropriate support to enable them to continue to give care. If there is a generalised lack of understanding in the more usually experienced care situations, it is of even greater importance that the acute emotional and physical problems faced by mothers caring for a son or daughter with life-threatening illness are acknowledged. It is possible to see an exacerbation of damaging health effects given the uniquely challenging nature of accompanying a son or daughter on the cancer journey – yet those very circumstances result in mothers’ reluctance to acknowledge their needs or allow the ‘time to be ill’.

There is much research on the health needs of carers (Lee 1998, Maher & Green 2002, Hirst 2004) and the health needs of the chronically ill (Charmaz 1997). Nevertheless, the combination of caring for a son or daughter with cancer, coupled with the emotional and physical labour demanded, and the likelihood of a gendered division of labour within the household adding to tensions, conspire to construct a unique set of circumstances. The health effects of such circumstances require recognition from professionals in order that sensitive and appropriate support may be offered if mothers are to cope both physically and emotionally with the cancer journey.

The NICE guidelines (2005) acknowledge that a family is likely to be thrown into crisis by a cancer diagnosis in this age group, and that the necessary support for the family is complex and multidimensional in nature. There is recognition that multi-agency patterns of support are needed, but that such provision has relied heavily on voluntary sector funding (p. 85). It would seem from the data presented in the present study that a variety of professional expertise is necessary to recognise needs which may remain unarticulated or unrecognised by those very people who are in need. Thus, sensitivity to the unstated, nuanced health effects of caring require a level of awareness amongst professionals that should be factored into the financial calculations of supporting a family through such a crisis. The NICE guidelines recommend that a social worker should be appointed to ensure that the needs of the wider family are met, and perhaps it is at this level of input that training relating to the recognition of the sometimes non-specific and vague symptoms should be included. If such symptoms are addressed, without being pathologised, at an early stage, this may mean that appropriate support can be introduced that may prevent the ‘normal’ illnesses of the mothers becoming ‘real’ illnesses.

The data presented here are based on a small, self-selected sample; however, issues are raised which would allow further research to be undertaken, perhaps taking a quantitative approach to ascertain how generalisable the experience presented in this paper is amongst the wider population.

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