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The work of living with a rare cancer: multiple myeloma

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The work of living with a rare cancer: multiple myeloma

Abstract

Aim To report findings from a qualitative study of the experiences of long-term survivors of multiple myeloma. **Background** Multiple Myeloma is a malignant disease of the bone marrow. Until recently, it was rapidly fatal. Although it remains incurable, people diagnosed with it are living longer on average, largely due to new treatments, some of which have onerous side effects. **Design** Prospective descriptive study. **Method** A series of 47 in-depth interviews were conducted at 6-12 month intervals over 18 months in 2008-2010 with 10 long-term survivors of myeloma and their primary support person. Interviews were analysed using the constant comparative method (Grounded Theory). **Findings** To adapt to the effects of both the disease and ongoing medical treatments, participants undertook extensive 'illness work'. Most of this work fell into two broad categories. Risk work aimed to mitigate risks to the well-being of both the person with myeloma and his/her carer. Emotion work aimed to manage the feelings of self and others in a protracted cycle of remission and relapse. **Conclusion** The experience of myeloma is increasingly characterized by issues associated with chronic disease and 'survivorship'. It is important for nurses working with people with myeloma to understand the overwhelming nature of illness work in this context. Nurses can put in place supportive measures to address the two main 'drivers' of this work: constant risk to well-being of survivors (including carers) and the recurrent need to manage emotions in social interactions.

Keywords

Cancer, carers, enduring illness, nursing, patient perspectives, qualitative approaches, risk management, work organization

Disciplines

Medicine and Health Sciences | Social and Behavioral Sciences

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THE WORK OF LIVING WITH A RARE CANCER: MULTIPLE MYELOMA

ABSTRACT

Aim. To report findings from a qualitative study of the experiences of long-term survivors of multiple myeloma

Background. Multiple Myeloma is a malignant disease of the bone marrow. Until recently it was rapidly fatal. Although it remains incurable, people diagnosed with it are living longer on average, largely due to new treatments, some of which have onerous side effects.

Design. Prospective descriptive study

Method. A series of 47 in-depth interviews were conducted at six to twelve month intervals over 18 months in 2008-2010 with 10 long-term survivors of myeloma and their primary support person. Interviews were analysed using the constant comparative method (Grounded Theory).

Findings. In order to adapt to the effects of both the disease and ongoing medical treatments, participants undertook extensive ‘illness work’. Most of this work fell into two broad categories. *Risk work* aimed to mitigate risks to the wellbeing of both the person with myeloma and his/her carer. *Emotion work* aimed to manage the feelings of self and others in a protracted cycle of remission and relapse.

Conclusion. The experience of myeloma is increasingly characterised by issues associated with chronic disease and ‘survivorship’. It is important for nurses working with people with myeloma to understand the overwhelming nature of illness work in this context. Nurses can put in place supportive measures to address the two main “drivers” of this work: constant risk to wellbeing of survivors (including carers), and the recurrent need to manage emotions in social interactions.

Key words; Qualitative Approaches; Chronic Illness; Carers; Cancer; Patient Perspectives; Risk Management; Work Organisation; Nursing,

Why is this research or review needed?

- People diagnosed with multiple myeloma are living longer on average
- Little is known about the experience of living with myeloma into the longer term
- Myeloma is increasingly experienced as a chronic condition, and needs to be better understood in this way.

What are the key findings?

- Living with myeloma requires effort, planning and organization particularly with regard to managing risks of injury and infection, and managing emotions.
- Living with myeloma creates work for both the person diagnosed with myeloma and for their significant other, and lay carers face specific risks
- People diagnosed with myeloma and their carers gain expertise over time in managing risk, managing the emotional toll and in mitigating the impact of the condition

How should the findings be used to influence policy/practice/research/education?

- Health care professionals should be aware that people living with myeloma might sometimes be overwhelmed by 'illness work', and they should be alert to the specific difficulties and risks faced by lay carers.
- Myeloma is increasingly experienced as chronic illness rather than a 'terminal' cancer, and this should be reflected in education and support provided to patients and their lay carers.

Introduction

Multiple myeloma is a rare life-threatening haematological cancer. In the 1990s, people diagnosed with it could expect to live for about 2.5 years (Durie et al., 2003). Although it remains incurable, the expected duration of survival has increased over the past two decades to 5-7 years, largely due to the availability of new treatments. (Kumar et al., 2007, Rajkumar, 2011a, Rajkumar, 2011b). There have been few studies of the experience of multiple myeloma, and even fewer that focus on living with myeloma rather than dying from it. We therefore undertook a qualitative study of long-term myeloma survivors and their primary carers. Our use of the term ‘survivors’ is consistent with extensive literature exploring the experiences of people with a wide range of cancer diagnoses (see, for example, (Feuerstein, 2008, Hewitt et al., 2005, Jefford et al., 2013). We report here on findings related to the very specific kinds of ‘work’ that cancer survivors do to adapt to their illness and the effects of ongoing treatment. This ‘work’ is often invisible to clinicians. Understanding the demands and nature of this work can inform supportive care.

Background

Myeloma is an incurable but treatable malignant plasma cell disorder. People with myeloma usually develop bone lesions, hypercalcaemia, anaemia, immunosuppression and renal impairment accompanied by fatigue and pain. The goals of treatment are to control the disease, secure remission and maximise duration and quality of life.

Treatment usually involves a course of chemotherapy and (for ‘eligible’ patients) a stem cell transplant (Durie et al., 2003, Kumar et al., 2003, Rajkumar, 2011b). Effective new treatments include a new class of drugs known as ‘novel agents’ that specifically target malignant cells (Kumar et al., 2008, Podar et al., 2008). The addition of ‘novel agent’ drugs, such as thalidomide, lenalidomide and borteomib, often combined with cortico-steroids, has improved survival for people with myeloma - but not without cost. These drugs have significant adverse effects (Mohty et al., 2010, Potrata et al., 2010, Potrata et al., 2011) and so demand complex adjustments to everyday life.

The illness trajectory for an individual with myeloma is typically characterised by periods of symptomatic disease that require treatment, followed by periods of remission with little or no treatment. Over time, periods of remission shorten (in between courses of treatment), the myeloma becomes refractory (i.e. nonresponsive to therapy), and the individual eventually succumbs to progressive disease.

Of the few studies that have focussed on the experience of myeloma, most have concentrated on the early treatment period (Fine Dahan &Auerbach, 2006) in which symptom management and the side effects of bone marrow transplantation loom large (Potrata et al., 2010, Potrata et al., 2011). Little attention has been paid to the experience of survival in the longer term (Maher &De Vries, 2011).

As is the case with other malignant diseases, the profile of multiple myeloma increasingly fits that of a chronic illness as long-term survival improves (Tritter &Calnan, 2002). Corbin and Strauss (1985; 1988) found that chronic illnesses typically require effort, skill and knowledge on the part of those who have to live with their effects. They characterise this as ‘work’, and differentiate between illness work, everyday life work and biographical work. The process of integrating the demands of illness work into everyday life for people with chronic illness has been variously conceptualised as ‘accommodation’ (Corbin, 1988), ‘integration work’ (Whittemore &Dixon, 2008) and ‘self-management work’ (Kralik et al., 2004, Kralik et al., 2006). Recent literature on chronic disease has tended to favour the discourse of ‘self management’, notwithstanding some concerns about political imperatives and their impact on patients and their families (Hinder &Greenhalgh, 2012, Kendall &Rogers, 2007a).

Self-management has been described as a participatory process in which patients and clinicians develop strategies together (Barlow et al., 2002) to equip patients with the skills and knowledge to manage the impact of the condition, monitor their disease and make effective use of support services outside of the clinical setting. This emphasis is also evident in the literature on cancer survivorship, and in the discourse surrounding supportive cancer care (Cockle &Hearne &Faithfull, 2010). Self-management interventions aim to ‘empower’ survivors and their families through access to information, education and practical, acceptable strategies to enhance well-being and recovery (Loh et al., 2013, Harris M et al., 2008). Cancer survivorship thus involves a particular kind of ‘work’ that involves acquiring skills and knowledge. In Australia, people living with myeloma are increasingly expected to take some of the responsibility for their own care (Gao &Yuan, 2011, Koller et al., 1996, Macdonald &Anderson, 1984, Kendall &Rogers, 2007b), and this self-management work can also significantly affect the lives of those closest to them.

The work of ‘self management’ can include managing one’s own emotions. Emotion work is evident among people affected by cancer, particularly in relation to the task of disclosure (Yoo et al., 2010, Gray et al., 2000) and caring for children with cancer (Clarke, 2006). Other manifestations of emotion work among people affected by cancer include managing fears and anxieties around burdening others (Ashing-Giwa et al., 2004); managing fear of recurrence and death (Crouch &McKenzie, 2000) and generally maintaining ‘emotional equilibrium’ (Ganz, 2007) during and following a cancer diagnosis. Informal carers in close personal relationships often have little choice but to engage in emotion work (Thomas et al., 2002).

We report here the findings of a qualitative study that aims to explore the experiences of long-term survivors of myeloma through in-depth interviews with people living in and around Sydney, Australia. In order to focus on long-term survivors, the study is based on the experiences of people who have had their first 'relapse' after a period of remission. The study also sought to account for the social dimensions of the experience, particularly the impact on partners and close relatives.

THE STUDY

Aim and design

The study aimed to develop a rich, empirically grounded description of the experience of living with myeloma after the first relapse, in the era of 'novel agents'. This required a qualitative approach that facilitated ongoing engagement with participants who were willing to describe their experiences in detail. Given the exploratory nature of the study, we used grounded theory methodology, and interviewed patients and their primary support person in order to examine the effects of myeloma on primary relationships.

Sample and participants

The study was conducted in three haematology departments in Sydney, New South Wales (NSW). Patients were eligible for the study if they were at least 18 years of age, diagnosed with relapsed or progressive myeloma following initial induction therapy, and able to speak English well enough to participate in an in-depth interview. We recruited a convenience sample (Morse, 2010) of participants and stopped recruitment once we reached theoretical saturation (i.e. no new insights were emerging from the data). Names used throughout this paper are pseudonyms.

Treating physicians asked eligible patients if they were willing to be invited to participate in the study. If the patient indicated that she or he was willing to participate, the physician provided the patient's contact details to the interviewer, who was not involved in their care or treatment. The patient was then sent a Participant Information Statement, Consent Form and a stamped return envelope. They were also invited to nominate a primary support person who was also sent the Information Statement and asked to sign a Consent Form.

Data collection

Interviews were conducted over 18 months during 2008-2010. The interviewer (MS) is a registered nurse with 25 years clinical experience in haemato-oncology and experience conducting in-depth interviews with cancer patients. A schedule of opening questions was compiled based on previous qualitative studies into illness experiences (Charmaz, 2006) and the previous experience of the research team. Follow-up questions were spontaneous. Interviews were conducted at a location of the

participant's choice, usually in their homes. Patient and carer interviews were conducted separately but at the same time points. Interviews were audio-recorded and sound files were transcribed verbatim. Identifying information was later removed from the transcript.

Ethical considerations

The study was approved by Human Research Ethics Committees of the university and participating hospitals. Counselling support was made available in case participants became severely distressed during or following interviews. Written consent was obtained at the first interview, and process consent (Ramcharan & Cutcliffe, 2001) adopted for the duration of the study by confirming participant agreement at each contact.

Data analysis

We conducted an inductive analysis using the constant comparison method (Charmaz, 2006). In keeping with a grounded theory approach, we began the analysis as interview transcripts became available. This allowed the interviewer (MS) to ask questions in follow-up interviews that probed topics or themes that we deemed to be of particular interest and importance given the aims of the study. This was consistent with the grounded theory tenet of theoretical sampling (Holton, 2007, Charmaz, 2006). As new categories and concepts developed through analysis, we retrieved relevant literature so the analysis was informed by existing evidence. Data were managed using a code-and-retrieve software program designed for qualitative analysis.

Rigour

Throughout the study and analysis, the findings and analysis were shared with people affected by myeloma attending Myeloma Foundation of Australia (MFA) support groups and educational days. Attendees were asked to comment on whether the findings represented their experiences. Attendees evaluated the findings as 'helpful' and 'insightful'. Comments such as 'it made me feel normal', 'yes, that is what it is like' and 'I am not alone', suggest that the findings were valid. The interviewer (MS) also compiled field notes, memos and analysis logs, and discussed emergent findings with more experienced researchers (CJ and HMCK).

Findings

The first author interviewed 21 participants (11 patients and 10 carers) up to three times at six to 12 month intervals. There were 10 patient/carer dyads, plus one additional patient. Separate interviews were conducted with each participant and on average took 46 minutes (12-78 mins). We aimed to interview each participant on three occasions over a period of 12-18 months. Twelve of the 21 participants declined to be interviewed at different times. Two patient participants died during the study: Anne died shortly after her first interview, before her daughter had been interviewed; David

died and his wife felt unable to continue in the study after this. One participant, Barry, was lost to follow-up after the first interview. In total, 47 interviews were conducted (Table 1).

Table 1. Participants: pseudonym, relationship, role, and number of interviews

Participants, in their dyads	Relationship	Role	Number of interviews
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Anne		Patient	1
Barry	Husband	Patient	1
Brenda	Wife	Carer	2
Clive	Husband	Patient	3
Celia	Wife	Carer	3
David	Husband	Patient	2
Delia	Wife	Carer	1
Etna	Mother	Patient	3
Emma	Daughter	Carer	3
Fred	Husband	Patient	3
Fatima	Wife	Carer	3
Gary	Son	Patient	2
Gertie	Mother	Carer	2
Harry	Husband	Patient	2
Helen	Wife	Carer	2
Ivan	Partner (male)	Patient	2
Ismelda	Partner (female)	Carer	2
John	Husband	Patient	2
Jane	Wife	Carer	2
Kira	Mother	Patient	3
Kerry	Daughter	Carer	3
Total			47

The work of living with myeloma

Myeloma created work and affected existing work. Extra work was created by the demands of busy treatment schedules, hospital visits and onerous drug regimens. Because myeloma reduced the capacity of participants to maintain their usual lifestyle, they had to expend more effort to accomplish tasks that were formerly routine and easy. These came to require detailed planning, effort and organisation to make the best use of time and energy (which became increasingly scarce) and reduce risks to wellbeing. Overall, our analysis identified two particular kinds of work as the main demands on participants: risk work and emotion work.

Risk work

Risk work typically took the form of vigilance (or self-surveillance) and risk evaluation. It enabled participants to manage the impact of myeloma and its treatment on their health and wellbeing, and over time, they integrated this risk work into their everyday lives.

Prior to diagnosis, most participants had not heard of myeloma. After the diagnosis was confirmed, they gathered information from a variety of sources including other people affected by myeloma, health care professionals, non-profit organisations, the media, the internet, and friends and family. They became discerning in their use of information; they evaluated its accuracy according to their own experience and context, and they decided which sources of information were trustworthy and pertinent to their particular situation. In short, they gradually became ‘experts’ in their own illness.

There were four foci of risk work: risk to general wellbeing; risk of injury; risk of infection; and risks to the carer’s ability to continue to provide practical support.

Risk to wellbeing

This category encompasses health promotion activities and general measures taken to mitigate the adverse impacts of myeloma and its treatment on wellbeing. Maintaining an adequate fluid intake was a particular concern:

I never drank water before, never did. At first it was hard, but now I drink it. I’ll get up in the morning, that’s the first thing I’ve got near the dressing table there and I won’t even go for the coffee. Water or green tea, that’s all I drink (Etna).

Diet was also commonly a consideration. Some participants had paid little attention to this before diagnosis, but afterwards ate only organic foods, avoided processed foods and/or supplemented their diet with vitamins. Some also paid close attention to sugar in their diet to manage high blood glucose levels caused by steroid treatment. Many participants saw physical activity and exercise as important means to aid recovery, rebuild strength, reduce complications and thereby return to enjoyable activities.

Participants managed adverse effects of treatment by manipulating medication schedules, particularly those related to thalidomide and corticosteroids. Steroids that were taken in short courses at high doses (i.e. “pulsed”) were seen as the greatest risk. Participants sometimes changed their medication schedules to control the timing of the dose. For example, Ivan increased the period between courses of steroids to gain relief from their effects: *‘You’re supposed to take it every seven days, which is a bit wrong but sometimes I’ll pull it back one day just to give me a bit of relief’*. Participants often said they felt ‘awful’ the day after their steroid regimen finished, and managed this by planning to be ‘out of action’ for several days or by changing their medication schedule to fit in with their plans. If there was a particular event planned, they took their steroids either on the day of the event, which allowed them to feel well on that day, or earlier or later than scheduled so that they did not have the effect of ‘withdrawing’ or ‘coming down’ on the day. Managing adverse effects of treatment became an ongoing part of participant’s lives.

The three main specific threats to participants’ wellbeing were those of infection, injury and anything that compromised the ability of the primary carer to sustain that role.

Risk of injury

In order to maintain their independence, participants had to maintain their ability to perform activities of daily living. This required them to manage the risk of injury, and in practical terms this meant learning to manage the impact of peripheral neuropathy, fatigue and fragile bones. Peripheral neuropathy posed a particular risk because it caused numerous complications, including ataxia, instability, difficulty gripping things, and sensory changes.

I was having problems, absolutely terrified I was on the bus because the bus drivers will not wait for you to sit down for a start, and if I couldn’t get onto a seat where I could hold on to something, I just felt useless. I felt so scared that I was going to fall and break something that I stopped going on the bus (Kira)

Over time, participants came to understand their own physical limitations. It was seen as important to learn to accept them and find ways to continue activities of daily life within these limits:

I’ve learned acceptance of everything more and probably created a little world of my own in a way that’s easy for me to live’ (Kira)

The weeds, I manage to get the weeds ... I find I don't get down on my haunches, I actually bend over to pull the weeds, I don't have to go down on my haunches now I can't but I'm capable of bending over to do it still (Fred)

Risk of infection

The risk of infection was also a constant concern because each participant was immunosuppressed due to the myeloma and/or treatment. Anne, a nurse by profession, described how she avoided certain food and boiled her water in order to manage her increased susceptibility to pathogens:

I boil my water to drink. I guess the reason I did it probably more so because I was at risk of infection

Participants were also aware of risks posed by contagion:

I think he [Emma's son] had a throat infection and I went 'I'm not going anywhere near her [Etna] '. Usually when he gets it, I get it, no one else, just him and I always seem to be prone to throat infections, so I quarantined ourselves (Emma, carer for Etna).

Some participants supplemented and changed their diet to support immune systems and speed up its reconstitution.

Risks to carers

Carers and significant others also had to manage risks to their wellbeing. This required them to balance their own needs with those of the family and the person with myeloma. During the study, three partners were diagnosed with a serious health issue, and each prioritised their partner's wellbeing over their own health.

Carers also reported on the day-to-day risks that threatened their ability to provide support to their significant other. These arose from fatigue and emotional distress, and a lack of time to attend to their own health needs. Delia managed these risks by taking time out from her carer responsibilities:

There were times when I had to get out of it completely and either go out with my girlfriends, go to the shops, do something right and it had to be something that I wasn't thinking about—hospitals or David or home, work (Delia).

Emma was initially focused on the notion that myeloma was a 'terminal' illness and she was waiting for her mother to die. Mindful of having experienced depression previously, she feared that this 'waiting game' could put her at risk of another episode of depression. She sought to reduce this risk by changing the way that she framed the situation:

And I thought 'Well whether she's got one year, 10 years, 20 years—what? You're going to live like this [waiting for her to die]? I don't think so.

Instead of focussing on her mother *dying of* myeloma, she came to focus on the task of *living with* myeloma.

The toll on carers sometimes put relationships in peril. One couple spent four years just 'waiting for death'. When they realised that death was not imminent, Harry's reaction was to throw himself into his work regardless of his physical condition. His wife found this difficult and distressing to watch, and reached a point where she felt unable to continue:

And I did that—Harry didn't, he kept in this work, work, work, seven days a week, and we did actually have words over this and I said to him if you want to take that road you've got to take it on your own because I can't go with you anymore (Helen).

Emotion work

'Emotion work' refers to effort and skills brought to bear when there is a need to 'manage' one's own emotional responses as a way of caring for others (McKenzie & Crouch, 2004). Carers in particular described how they carefully 'managed' their responses when interacting with their partner. Pre-diagnosis, they were more assertive, openly acknowledging their own feelings and sometimes arguing the point. Post-diagnosis, they often made a conscious effort to 'bite their tongue' as a way of minimising the potential for conflict and reducing anxiety. As Fatima and Jane explained:

I kept quiet, don't upset him, let him go and I think that's where my strength really comes... you're relaxing yourself and saying well you know that's it I can see that he's getting a little bit uptight about it, I stop and calm the situation straight away. I don't go on like I used to (Fatima, carer for Fred).

I used to give him back. But now I sort of back away, you know, I let him have his say and go ahead and do what he wants to do (Jane, carer for John).

Managing – suppressing – one's own emotions in these circumstances requires effort, particularly given that carers themselves are likely to be experiencing feelings of anxiety, loss, uncertainty:

Sometimes it's hard because ... [I] try and say this and what's going to happen, and then I stop straight away, I say 'No, I can't deal with that, I'll deal with that later', you know, and I stop (Fatima, carer for Fred)

Participants with myeloma also engaged in emotion work. The effects of some medications, especially cortico-steroids, impacted on their emotional stability, and they had to work hard to manage outbursts of anger or other emotions:

Especially going through this particular medication [cortico-steroids], you sort of feel that you have to close your eyes and you need to stay calm sometimes (Fred).

Clinical consultations reminded participants of the life-limiting nature of their illness. They described how anxiety, sadness and fear levels escalated as the appointment approached, but their responses to these feelings needed to be managed if they were to appropriately function in the consultation. Feelings of shock, fear and disappointment arising from ‘bad news’ received at these times also required emotion work:

I’m starting to come to grips with it again, I’m usually a pretty positive person but I said to my daughter on Friday when we got the bad news [of relapse], I sobbed a day and then it’s onwards and upwards (Anne).

Oh it’s just, if you’re not feeling too crazy[and things] don’t go the way you want them .. you just either clench your teeth, lock yourself in the toilet and have a cry or just have an outburst, which probably isn’t the best, but just keep it short (Celia carer for Clive).

News of diagnosis, relapse or disease progression given to participants by their doctor had to be communicated to other family members. Disclosing bad news such as this required emotion management to mitigate distress, and the timing and flow of information was considered be important. Primary support persons frequently undertook this work, particularly in situations where their loved ones used avoidance as an emotion management strategy. For some participants, the only way to manage their distressing emotions was to avoid making disclosures themselves, relying on others to deliver the information while managing their own and others’ distressing emotions as part of that process:

[She] Couldn’t even talk about it, not talking about it, not telling anyone. Mum can’t talk about it, Dad can’t talk about it. Mum just gets upset and all in a mess and Dad was in denial.... then [I told my Mum’s sister] on a big hour phone call that morning before we visited (Emma, carer for Etna).

He said: ‘I’m going to Canberra. You can tell the kids while I’m gone.’ ... He couldn’t tell them. He couldn’t tell any of them. One time he just went away for three days and didn’t come back, and it was terrible (Helen, carer for Harry).

Discussion

The experience of myeloma entails constant physical and emotional effort for both the ill person and also their primary carer. This ‘work’ has not featured in previous qualitative studies of myeloma because, until recently, the duration of survival was usually brief. The experience was thus dominated by the impact of what was widely characterised as a ‘terminal’ diagnosis. As effective new treatments (‘novel agents’) have become available, the trajectory of the illness (Rajkumar, 2011a, Rajkumar, 2011b) has changed significantly. As people are living with myeloma for longer, it is increasingly experienced as a ‘chronic’ illness, and people diagnosed with it are focussed more on the challenges of living with the disease and the adverse-effects of the treatments than they are on the prospect of dying.

Chronic illness is a long term experience that engenders uncertainty and intrudes into an individual’s everyday life (Larsen, 2009). The specific challenges and demands vary but there are commonalities. These include recognising symptoms and changes, managing medications, managing psychosocial wellbeing and managing interactions with health care systems. These have been characterised as ‘self-management processes’ (Wagner et al., 2001, UK Department of Health, 2003, Schulman-Green et al., 2012, Kralik et al., 2004). This term tends to understate the effort demanded everyday of participants in this study, some of whom likened their experience of survival to an arduous and relentless endurance race.

Our analysis of the illness work associated with myeloma shows that it is chiefly aimed at mitigating risks of injury and infection. This finding reflects the specific ongoing effects of a disease that causes fragile bones and susceptibility to infection due to immune suppression. Our findings also reveal how myeloma can indirectly affect the health and wellbeing of carers.

Participants invested time and effort adapting to and managing risk in the face of unpredictability and change. Vigilance was constant and everyday decisions frequently entailed detailed risk assessments. Participants with myeloma and their carers constantly worked to manage the illness and reduce its impact on their own and each other’s wellbeing. They analysed risks in terms of what might or might not happen in their personal situation, and rarely described risk in terms of statistical probability. This is in keeping with a sociological concept of risk (Sanders, 2004).

The burden of work that is evidently assumed by both the person with myeloma and their carer is concomitant with the active role that people with chronic illnesses are increasingly expected to assume (Gao & Yuan, 2011, Schulman-Green et al., 2012, Kendall & Rogers, 2007b). The ill person becomes a “relay” of the medical gaze (Jordens et al., 2010) by becoming vigilant about their own health, or the health of the ill person they are caring for. They cease to rely on professionals to evaluate risks and recommend remedial action; they monitor their own bodies, impose their own dietary and exercise regimes, and even modulate their own medications. As well as being a consumer of medical information they become a producer of a hybrid form of knowledge—one that synthesises personal experience and information gleaned from a variety of medical and non-medical sources. This is at

odds with the conventional, biomedical model in which expert professionals offer the ‘best’ treatment or management plan (Kendall & Rogers, 2007b). In order to juggle and successfully manage competing demands on time, available energy and resources, both patients and carers have to cultivate organisational skills as well as knowledge; the illness forces them to become their own risk managers as well as their own healers.

Our analysis also shows that the ‘work’ of myeloma includes intensive emotion work. The concept of ‘emotional labour’ was originally defined by Hochschild as that which “requires one to induce or suppress feelings in order to sustain the outward countenance that produces the proper state of mind in others” (Hochschild, 1983)pp.7). Hochschild was primarily interested in the commercialisation of emotions within service industries. Others have since used this concept to examine how people manage emotions in personal situations, including illness (Barbalet, 1998, McKenzie & Crouch, 2004, Duncombe & Marsden, 1998).

Frank (2007) draws attention to the potentially alienating nature of emotion work involved for some in living with disability and serious illness. Sensing the social imperative to present themselves ‘positively’, ‘people foster impressions in order to make the most extensive, but still defensible, claims for their selves’ (2007, pp382), an effort that often requires suppression of challenging emotions. According to Yoo et al (2009), women living with breast cancer manage their own emotions to protect their loved ones from experiencing negative emotions, and to protect themselves from being labelled as dependent or in some sense guilty.

Both patient and carer in our study actively managed their own emotions (Barbalet, 1998) to protect others or to try and improve their own mood state, which, in the case of patients, could be affected both by the seriousness of their situation and also the effects of corticosteroid medications. Patients clearly tried to control the expression of challenging emotions such as anger or fear, which may be exacerbated by medications. Given the characteristic cycles of remission and relapse, there is often the need to ‘break the bad news’ to others. This task is usually taken on by primary support persons, a responsibility that inevitably involved emotion work. More generally, primary support persons shared the emotional impact of the illness experience and presented the emotional struggle of living with myeloma cancer as a joint one (Thomas et al., 2002).

Finally, our analysis suggests that if myeloma has become more like a chronic disease, it is a particularly demanding one and it sometimes leaves little space for anything else. In terms of Corbin and Strauss’s original taxonomy, illness work expands to fill the space of everyday work.

Study Limitations

These research findings were generated in an exploratory qualitative enquiry from a cohort of participants who were not randomly selected. The interviewees were all English-speakers who lived

in the suburbs of Australia's largest city. Therefore our findings should not be generalised to wider populations without being replicated in larger studies that are more representative of the general population.

Conclusion

For people diagnosed with myeloma, novel agents have contributed to the quality and duration of survival. Based on a series of in depth interviews with survivors, we found that the experience of survival in the longer term is characterised by intensive 'illness work' that is typical of chronic illness, particularly risk work and emotion work. Living with myeloma demands relentless effort, planning and organisation, and constant vigilance about risks of infection and injury, and risk to the general wellbeing of both patient and carers. It also requires intensive 'emotion work' from both patients and carers. The payoff of this work is that, over time, people diagnosed with myeloma often come to understand their own physical limitations and develop strategies for managing intense fatigue, distressing emotions, pain and neuropathy while continuing to go about their daily business.

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