“So, are you back to work yet?” Re-conceptualizing ‘work’ and ‘return to work’ in the context of primary bone cancer

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ABSTRACT

People with primary bone cancer typically are young (usual age-at-onset 16–35 years old) and undergo arduous treatments. The current standard of care (tumour resection and limb reconstruction with or without chemotherapy) results in survival rates in excess of 60%, but also results in significant disability at a time when patients are choosing career paths, establishing their independence and embarking on new roles. To date, the nature of the relationship between experiences of osteosarcoma illness and experiences of vocation has remained unclear. This study sought to examine this relationship using qualitative narrative methodology. In-depth audiotaped interviews were conducted with 14 osteosarcoma survivors (8 men, 6 women) who were being treated at Mount Sinai Hospital, Toronto, Canada. Interview transcripts were analyzed for story typology and thematic content via constant comparison. Respondents reported engaging in three types of ‘work’: ‘illness work’, ‘identity work’ and ‘vocational work’. Osteosarcoma illness represented a crisis for respondents, one which necessitated considerable illness work. Illness work was portrayed as all-consuming, whereby respondents were forced to stop vocational work for considerable periods. The illness crisis also precipitated ‘identity work’. Respondents recounted a transformative process, of ‘becoming other’ to whom they had been prior to illness. As a result, respondents told of re-entering the vocational sphere with a different sense of themselves from when they left it. When patients return for surgical follow up, clinicians routinely ask, “So, are you back to work yet?” expecting simple ‘yes/no’ answers. This study suggests that the answer is instead highly complex, and that patients could be seen as having been ‘working’ all along. This study offers a re-conceptualization of ‘work’ and ‘return to work’ in the context of osteosarcoma, with implications for clinical and return-to-work practices.

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Introduction

Primary bone sarcomas are malignant tumours occurring most commonly in the metaphyses of long bones, the majority arising in the lower extremity (Campanacci, 1990).

Patients are typically young – the most common age of disease onset being between 16 and 35 years – with long-term survival rates in excess of 60% (Levesque et al., 1998; Skubitz & D'Adamo, 2007). The current standard of care is limb preservation surgery with or without adjuvant chemotherapy (Malo et al., 2001; Skubitz & D'Adamo, 2007). The extent of the surgical intervention (tumour resection and limb reconstruction) coupled with the toxic effects of chemotherapy mean that patients frequently experience significant disability and health status alterations postoperatively, including the ability to engage in premorbid vocational roles (Brown et al., 2003). Most of these patients are at a period of their lives of high physical, social and economic demands, thus vocational pursuits are a major concern.

Despite the burden of illness and its treatment, there is a dearth of literature regarding 'return to work' (RTW) in the osteosarcoma population. Only two studies have been conducted previously. Rougraff et al. (1994) reported that 69% of their sample ($n = 29$) had returned to paid work at 12-year follow up (Rougraff, Simon, Kneisl, Greenberg, & Mankin, 1994). However they did not relate RTW to premorbid work status and the long follow-up period makes it difficult to draw conclusions regarding the timing of RTW relative to treatment interventions. Brown et al. (2003) found that 25% of their sample ($n = 36$, distal femoral tumours) experienced detrimental changes in work status up to 9 years post-treatment. Work-status trajectories were mapped over time to determine whether survivors followed an 'expected' or 'unexpected' course relative to premorbid work status and age-at-disease-onset. Heavy physical job demands and living in rural environments were predictive of difficulties resuming premorbid work roles (Brown et al., 2003). However, this retrospective pilot study could not address the role played by individual experiences and preferences in resumption of work postoperatively. Moreover, it raised questions about how to define 'work' (40% were students at baseline), and what might constitute 'successful' RTW outcomes from patients' perspectives. Some participants resumed their studies postoperatively, while others went on to pursue paid employment. This research led directly to the question addressed here: what is the nature of the relationship between experiences of osteosarcoma illness and experiences of resuming vocational pursuits?

A focus on language is central to our conceptualization of the present study. Our use of the term 'vocational pursuits' is significant, signaling our attempt to distinguish between what is meant by 'work' and 'RTW' in the context of osteosarcoma, and to challenge some of the assumptions underlying these concepts. Much of the RTW literature defines 'work' as synonymous with paid employment, and this attention has been warranted, since inability to engage in income-generating pursuits carries considerable socio-economic and personal costs (Hansson, Bostrom, & Harms-Ringdahl, 2006; Schroer, 2005; Schweigert, McNeil, & Doupe, 2004). Moreover, the majority of RTW investigations have emphasized *returning* to paid employment as the outcome of interest (usually full-time, usually to premorbid roles, and frequently dichotomized as 'returned' or 'not returned') (Arnetz, Sjogren, Rydehn, & Meisel, 2003; Martin, Brooks, Oritz, & Veniegas, 2003; Schroer, 2005; Yasuda, Wehman, Targett, Cifu, & West, 2001). However, such overly

simplistic definitions neglect other pursuits that are important to individuals – part-time work, unpaid work (e.g. homemaking, volunteering), training/apprenticeship, and education. Some investigators define 'successful' RTW as returning to the same job or the same job with modifications (Manktelow, Binhammer, Tomat, Bril, & Szalai, 2004), while still others have included variations on this theme (e.g. duration of absence, returning to reduced hours) (Pransky et al., 2000; Satariano & DeLorenze, 1996). Shifts in vocational role post-illness have rarely been studied. Review of the literature reveals little agreement as to the best way to define and operationalize outcomes.

Social scientific approaches to 'RTW' have been more successful at capturing the complexity of the RTW process than biomedical approaches. Social scientific approaches are leading some investigators to recognize RTW as not strictly a biophysical/medical process, but as the product of multiple influences (social, psychological, environmental) (Franche & Krause, 2002; Frank et al., 1998). The contributions of qualitative sociology are particularly informative, as these privilege the accounts of recovering individuals and inform our understanding of the meaning of 'work' and 'RTW' in their lives. Qualitative investigations with various populations have emphasized important psychosocial features of work/RTW, including workplace conditions and social relations, attitudes and beliefs (of workers, co-workers, supervisors, clinicians), decision-making behaviour, and social structural influences on RTW as an ongoing process (Baril et al., 2003; Eakin & Macheachen, 1998; Gard & Larsson, 2003; Shaw, Robertson, Pransky, & McLellan, 2003). This recognition of RTW as a social process is essential to our conceptualization of the research problem – acknowledging the implications of vocational roles for identity/self-definition and the role of pre-illness experiences (Braveman, Helfrich, Kielhofner, & Albrecht, 2003; Ezzy, 2000; Nixon & Renwick, 2003). The potential influence of gender (e.g. in terms of vocational expectations) is also recognized (Smith, 1998; Sparkes & Smith, 2003; Znajda, Wunder, Bell, & Davis, 1999). Societal expectations/discourses surrounding RTW are integral to this framework, extending back to Parsons' conceptualization of the 'sick role' (Parsons, 1951). Since Parsons (1951), there has been an understanding that illness sanctions individuals to stop employment and other vocational roles (at least temporarily) in the interest of 'getting better'. This notion of the 'job of illness' (Corbin & Strauss, 1988; Herzlich & Pierret, 1987) is important to our conceptualization of RTW in the setting of osteosarcoma.

Recognizing the complexity of RTW processes and informed by the social scientific approaches outlined above, we employed a qualitative methodology for this study. The specific objectives were (1) to characterize the lived experiences of illness of people with osteosarcoma; (2) to characterize the lived experiences of resuming vocational pursuits in the context of osteosarcoma; and (3) to understand and explain the relationship between these experiences.

Methods

Conceptual underpinnings

A postmodern narrative methodology was adopted – an approach which downplays dominant biomedical accounts,

privileges patients' perspectives, and reflects the contingent nature of lived experiences (Frank, 2002; Morris, 1998). Narrative mediates between the outside and the inside of the person, highlighting the interconnections between experience, meaning, time and accounts (Crossley, 2000; Garro & Mattingly, 2000; Reissman, 1993). The potential to explore the *meaning* of experiences of osteosarcoma illness and vocation, and how such meanings might change through time, were advantages offered by narrative methods (Crossley, 2000; Frank, 1995; Garro & Mattingly, 2000).

Stories are evaluative and explanatory and can be interpreted as "moral arguments" – speaking to how one 'ought' to behave under certain circumstances (Garro & Mattingly, 2000: 11). These evaluative features make narrative approaches well-suited to studying RTW, whereby 'work' (vocation) is frequently framed in terms of social capital, and as an integral part of citizenship and human worth (Behtoui, 2007; Nixon & Renwick, 2003).

A number of 'sensitizing concepts' from narrative theory informed the study's design and analysis (Frank, 1995, 2001; Morris, 1998; Ricoeur, 1992). Frank's concepts of 'narrative typology' and 'suffering as a process of 'becoming other'' were particularly important (Frank, 1995, 2001). Frank argues that patients tend to recount illness narratives in one of three primary styles (restitution, chaos or quest), with elements of style being linked to individuals' particular contexts. This sensitized the researchers to listen for different styles of narration. A comparison of our findings with Frank's framework will be the focus of a forthcoming article and will not be emphasized here.

Ricoeur's depictions of suffering, agency and the relation of narrative to identity were also important to the analysis, as respondents' accounts of their identities emerged during the course of the study (Ricoeur, 1992).

Study procedures

The study protocol was reviewed and approved by the Research Ethics Boards at Mount Sinai Hospital and University of Toronto (Toronto, Canada). All data were anonymized and individuals' stories are presented using pseudonyms.

One-time, in-depth interviews were conducted with 14 bone tumour survivors (8 men, 6 women, age-at-diagnosis = 16–35 years). The principal investigator (JP) conducted all interviews. Respondents were encouraged to tell their stories emphasizing any aspects they wished, with the interview guides providing broad topic areas for discussion (e.g. vocational experiences – and plans – pre-diagnosis and post-treatment, daily routines 'then' and 'now', arriving at diagnosis, illness experiences).

Respondents were identified from a database of bone tumour patients treated at Mount Sinai Hospital (limb-preservation surgery and chemotherapy). Theoretical sampling (informed by prior research with Brown et al., 2003) was employed. To achieve sample heterogeneity respondents were sought with different socio-demographic profiles (e.g. mixture of men and women, varied premorbid work statuses, educational and ethnic backgrounds) and clinical characteristics (e.g. upper- versus

lower-extremity tumours) (Brown et al., 2003; Davis, Bell, Badley, Yoshida, & Williams, 1999). As analysis progressed and became increasingly focused on identity and various forms of 'work', it became important to determine if respondents' accounts were influenced by time since treatment, age, life stage, etc. Thus the final sample included individuals ranging between 1 and 6 years post-operatively, and with varied combinations of age-at-diagnosis, gender, and parental status. Table 1 profiles the 14 study participants.

The interview setting was based on respondent preference, with various settings used. Most interviews lasted between 75 and 90 min (range = 40–180 min), and were audiotaped and transcribed. Detailed field notes were written following each interview.

Data analysis occurred in conjunction with data collection. Initially, interview transcripts were read in their entirety and notes made. Transcripts were then coded line by line to explore emergent themes (Kvale, 1996). A strategy of multiple readings was adopted (Pamphilon, 1999). At all levels of reading, interview stories were cross-compared in terms of tone, content and form (Reissman, 1993).

Approaches for ensuring analytic rigour included checking, questioning and theorizing (Kvale, 1996). Surprises in the data that challenged *a priori* assumptions were interrogated, 'negative' cases examined, and alternative explanations explored (Kvale, 1996). Subsets of transcripts were reviewed independently by the co-investigators (and by an independent researcher) with a view to elaborating and refining emergent themes.

Findings

Conceptualizing 'work'

Prior to exploring the different forms of work depicted in respondents' stories, it is important to articulate the definition of 'work' employed in this study. 'Work' was conceptualized as synonymous with 'action with a sense of purpose' – connoting agency, active engagement, struggle, and intentionality. Dictionary-based definitions suggest it entails "creative effort" as well as "exertion that is difficult and exhausting" (Roget's Thesaurus, 1995). Drawing on prior conceptualizations from Corbin and Strauss (1988), 'work' entails tasks to be performed by specific actors under specific conditions. However 'work' consisted of much more than a catalogue of tasks to be performed, but also entailed the negotiation of social relations of work, as well as structural features (e.g. temporal, spatial and social organization of respondents' lives during hospitalization).

Three types of 'work'

Respondents recounted three kinds of work in which they engaged: *illness work*, *identity work* and *vocational work*. Illness was depicted by respondents as a crisis in their lives, characterized by intensive 'work'. The all-consuming nature of illness work was the primary reason offered by respondents for stopping vocational pursuits for considerable periods. For most respondents, vocational 'interruptions'

Table 1
Participant profiles ($n = 14$)

Name*	Age-at-diagnosis	Age-at-interview	Gender	Tumour location (extremity)	Ethnicity	Parental/marital status/living arrangements	Premorbid vocation	Postmorbid vocation	Duration vocational interruption	Comments
Josh	18	21	M	Lower extremity	Canadian (miscellaneous N. European)	No children/single; lives with parents/sibling (urban)	High-school student	University student	14 months	Reports greater vocational ambition post-illness
Derek	20	23	M	Lower	Canadian (N. European)	No children/single; lives with parents (small town)	Physical labourer (high-intensity)	Physical labourer (lower-intensity)	2 years	Plans pre-illness for new physically demanding career; abandoned plans post-illness; illness forced move back with family
Diane	35	38	F	Lower	Canadian (N. European)	Three children/married; lives with spouse/children (rural)	Part-time paid sedentary work, homemaker	Part-time paid sedentary work, homemaker	Gradual process resuming all roles Approximately 20 months (paid work)	
Vanessa	31	35	F	Lower	South-Asian-Canadian	One child/married; lives with spouse/child (urban)	Two full-time jobs before childbirth (service, white collar)	Full-time homemaking with outside assistance	Ongoing	Uncertainty re: ever returning to paid work
Melanie	16	18	F	Lower	Canadian (N. European)	No children/single; lives with parent (small town)	High-school student and part-time work	High-school student, & part-time work	Reported decreasing studies during treatment (not stopping); resumed P/T work approximately 19 months	
Maria Christina	24	26	F	Lower	Portuguese-Canadian	Two children/married; lives with spouse/children (urban)	Full-time physical labour (factory)	Full-time homemaker	Ongoing	Doubts she will ever be able to return to previous work
David	18	21	M	Lower	Caribbean	No children/single; lives with parent/sibling (urban)	Community-college student, planning sports career	University student	18 months	Illness led to abandoning sports career
Steve	21	24	M	Lower	Canadian (N. European)	No children/engaged; lives with fiancée and friend (urban)	Community-college student	Full-time work, chosen field (technical, white collar)	14 months	Illness led to abandoning valued leisure activities (sports)
Isabella	30	35	F	Upper extremity	Italian-Canadian	Two children/married; lives with spouse/children (urban)	Full-time homemaker	Full-time homemaker	Gradual process resuming role	Ongoing fatigue, paces self to fulfill role; uncertain regarding future P/T work
Sean	19	22	M	Lower	Canadian (N. European)	No children/single; lives with friends (urban/rural mix)	Apprentice (skilled trade)	Community-college student	24 months	Illness forced move back with parents; changed vocation
Labib	29	31	M	Lower	Middle-Eastern (student visa)	No children/single; lives alone (urban)	Graduate student	Graduate student	<1 year, but gradual return to full-time studies	Reports decreased ambition post-illness; uncertainty about prior career goals

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Table 1 (continued)

Name*	Age-at-diagnosis	Age-at-interview	Gender	Tumour location (extremity)	Ethnicity	Parental/marital status/living arrangements	Premorbid vocation	Postmorbid vocation	Duration vocational interruption	Comments
Sophia	25	31	F	Upper	Italian-Canadian	No children/single; lives alone (urban)	Professional	Professional	1 year	Reports no longer working '24/7'; priorities other than work post-illness; illness forced move back with parents
Carlo	22	27	M	Lower	Italian-Canadian	No children/single; lives with parent/sibling (urban)	Community-college student (skilled trade) and P/T work	Quit school, working full-time but impending layoff	18 months	Starting new career: writing and own small business (plans F/T)
Mark	31	32	M	Lower	Canadian (N. European)	One child/married; lives with spouse/child (urban)	Community-college student/apprentice (skilled trade)	Full-time homemaking	Ongoing	Reports struggling to resume apprenticeship

*Pseudonyms.

lasted at least 1 year, but frequently longer. The crisis of illness also precipitated important 'identity work'. Respondents told of 'becoming other' to who they had been prior to illness. As a result of these transformative experiences, respondents noted that they returned to the vocational sphere different from when they left it. As such, they recounted a changed relationship to vocation. All three forms of work identified will be addressed in turn, but all were intricately interwoven.

Illness work

The crisis of illness onset was depicted as the beginning of a new 'job' by participants. They were more than simply busy, active or struggling. Entry into treatment was analogous to entering a new workplace. Not only did respondents describe a series of necessary 'tasks' to be performed as they underwent treatment, but also a new social network of cancer colleagues (e.g. fellow patients, health professionals) with whom they interacted and performed these tasks.

Illness was portrayed as demanding 'work', which began upon diagnosis. Sophia recounted:

... [her surgeon] said, "Yeah, you have osteosarcoma. Now you have to stop working." So within those 2 weeks they did all these different types of tests – quite invasive. Then I started chemo, so I really had no time to think about it. A lot of people say ... "What did you get for a second opinion?" I really had no chance. They were just straight, you know, "do the biopsy, do this test, do this test, do this test." I had no time to think about it... (25 at diagnosis, 31 at interview).

Despite the initial shock of diagnosis, Sophia is called to action; she has a new job – the work of treatment. The surgeon's command to 'stop working' seems ironic, as Sophia becomes busily engaged with this new form of work.

Life on the cancer ward promoted a sense of dislocation from their lives as respondents had previously lived them. They recounted being isolated from their normal spheres of interaction: from family, friends and vocational work. They described being stripped of their pre-illness lives and bodies and entering an alien world. Josh reflected:

Non-stop testing. Probing and testing and, and before this whole thing I had never even set foot into a hospital. I've never broken a bone, I've never been treated for anything in the hospital before ... it was all a whole different world ... (19 at diagnosis, 22 at interview).

Participants' accounts were remarkably similar in terms of the procedures and routines involved in treatment. They employed 'insider jargon', using the language of the medical team to describe the rituals of treatment undergone. We interpreted these treatment rituals (including periods of isolation on the cancer ward) as 'rites of passage' (van Gennep, 1960), demarcating their social transition from the status of 'healthy young person' to that of 'cancer patient' (a consideration of the role of rites of passage is beyond the scope of this article). Respondents invariably told of profound changes to their bodies and social relations during this initial intensive phase of treatment, recounting these experiences as akin to journeying to a foreign land.

Finally, illness was also portrayed as an ordeal and a source of suffering. Suffering was depicted as not only physical, but also social, psychological and spiritual. While suffering is sometimes characterized as a passive process in the literature, these respondents depicted themselves as *active sufferers*. Mark commented:

But I always viewed cancer on a personal level as a choice. You get cancer, you can actually refuse cancer, you can choose not to have cancer, or you can choose to have cancer. And if you choose not to have cancer, you often try to fight it, and exhaust yourself on the fighting of cancer ... Choosing cancer is very simple – you just do. And then you allow the doctors to fight it ... I never did fight it. I removed myself. I kept my cancer healthy. Well, I assumed I kept my body health and my cancer as happy as possible. I concentrated on the battles I knew I could win, like eating my breakfast and not throwing it up 5 minutes later (31 at diagnosis, 32 at interview).

In this quotation, Mark uses active language to portray his encounter with illness. He *chooses* cancer and implies a conscious decision and effort in order to respond to suffering in this way. He speaks of “*keeping* his body healthy” and his cancer “as happy as possible”; he talks of concentration, intentionality, and invokes battle imagery – which produces a narrative tension in his interview between fighting and not fighting cancer (Mark had prior military experience). Even his notion of choosing and not choosing cancer is framed in terms of active choice. Later in his interview, Mark recalls the work he performed in managing the sequelae of chemotherapy (e.g. shaving his hair rather than watching it fall out). In Mark’s words, he “did many things”. Like Mark, other respondents portrayed themselves as active protagonists and illness workers.

Identity work

In recounting their stories of illness work, suffering endured and recovery accomplished – and of vocations lost and found – participants also told of who they were, who they were not, and who they would like to be (Frank, 2002, 2005). We termed this ‘identity work’ because it spoke to the active engagement, effort, and agency recounted by respondents – all directed toward coming to terms with the profound changes wrought by illness and to changes in how they viewed themselves (and how others viewed them). Illness acted as the catalyst for identity work, a process of ‘becoming other’ to who they had been prior to illness. Drawing on identity definitions of Ricoeur (1992), Charmaz (1995) and Frank (2002), we interpreted respondents’ accounts as reflecting not only personal and social facets of identity, but also ethical or moral aspects. Respondents went to considerable lengths to portray themselves as ‘worthy’ social actors, drawing on prevailing discourses of work ethics and stoicism in the face of the cancer ordeal.

Derek depicted his experience of identity transformation in highly positive terms – despite the fact he could no longer pursue his original career plans as a result of his illness, and despite his graphic descriptions of the “ordeal” he endured. Derek characterized the transformation as follows:

It’s made me a lot better person and I look at things a lot differently than I did. So I was talking with a friend...and she actually said ... life’s what happens when you’re planning for it, what happens between your plans. I thought that was great. Because you know I had all these plans. I thought this is how my life’s going to be and this is what I’m going to do. Whereas it’s taken away from you, and you just kind of have to deal with it. Figure out another plan, you know. I wouldn’t want to have to go through the whole ordeal again, but it’s not something I’m sorry I did...it kind of just made you realize what’s important and you just have to take what life gives you. And appreciate what you have I guess. I was, I was pretty lucky (20 at diagnosis, 23 at interview).

Derek speaks of encountering the contingency of illness as actively having to deal with it, of being adaptable to “figure out” an alternate plan. He uses the present tense and active language to suggest that the transformative process of identity work is ongoing. Like other respondents, Derek uses the term “ordeal”, yet indicates it is not an experience he regrets. Derek’s assertion that he recognizes “what really matters” and appreciates life as it is (rather than how it ‘ought’ to be) suggests a moral stance of which he is proud. Like other respondents, he stated “I was lucky” repeatedly during his interview.

Respondents drew on and responded to a variety of prevalent societal discourses (e.g. those surrounding youth, femininity, masculinity, parenthood) as they recounted the identity transformations in which they engaged. They demonstrated a sophisticated knowledge of such discourses, and actively weighed these as they explained how they had been profoundly changed by illness. They compared and contrasted themselves with their ‘healthy’ peers, speaking to social features of identity. For example, Sophia talked at length about being a woman experiencing disfigurement and disability (her upper extremity reconstruction resulted in considerable scarring and impaired function) in the context of a society that values unblemished feminine beauty and youthful independence. She spoke of negotiating her new identity within this context.

This is my arm now. I’m going to be living with it for the rest of my life. I’m still young ... And at the same time ... I feel like girls are conscious of their arms hanging. And I think, that’s nothing compared to this scar ... it’s much more evident. So I become more, “Why are you complaining about that? See this scar?” I’d like to see other people who would have this scar and how they deal with it. So it came to the point where, “Yeah, go ahead, look at it.” It’s on my body and that’s it.

She goes on to characterize her affected arm as “beautiful”, that she fully accepts and embraces its altered nature. Sophia portrays herself as actively and intentionally reconfiguring her identity in the wake of illness, noting that she is no longer “petty” or “complaining”. She is not merely reacting to her ordeal, it is not simply a burden she bears, rather she actively grapples with it and musters a response of which she is proud. Sophia portrays herself throughout her interview as responding with strength (“I’d like to see

other people ... deal with it"). She both challenges prevailing discourses of feminine beauty and reproduces them.

Not all respondents characterized their identity transformations in positive terms. Some recounted transformations which were profoundly distressing. For example, Labib remarked, "If I have to be honest, deep inside me, I think there's something fundamentally that's changed, and not changed for the positive" (26 at diagnosis, 29 at interview). Labib depicts a deep-seated transformation in his outlook, whereby his "whole personality" has changed. He describes 'becoming other' to his pre-illness self, but not always in ways he would wish. Prior to illness he had been an ambitious graduate student, but he described avoiding thinking about the future 2 years post-treatment. He noted that he changed from "proactive to reactive", which had implications for his relationship to vocation and his broader social landscape.

Although Labib reports ongoing distress, he too recounts identity transformation as an active rather than passive process. He is engaged in identity work, employing conscious effort to be the person he says he would like to be. While he disbelieves the surgeons' assurances that he is 'cured', he recounts being actively engaged in his life.

... one time I wanted to quit my study, but then the thing is that you know, even if it's a very short life, you've got still to live it. And once I realized that, things started being different ... and sometimes I wanted to be sick, to get the attention of people ... I probably should be brave enough to admit, to confess to that. But then right now, I think, no I would love to be, to live ...

Labib's account conveys the essence of identity work, a journey through difficult foreign terrain – of self-discovery, of admitting to things of which you are and are not proud. In his story, Labib works hard to dissect his experience, to make sense of it, and to articulate his current longings for the future. Throughout his account he talks about how he would and would not like to be. Despite significant personal losses, the language of opportunity keeps creeping into his narrative. He recounts how the experience of care and kindness from both health professionals and friends changed his "view of people" and that "it just made me feel that you should yourself, or I should myself, be just like any of these people, just trying to do any good that they can do". This propensity to employ moral language to describe their experiences, their own responses (and the responses of others) was characteristic of participants' accounts. Respondents proudly portrayed themselves as moral agents rather than passive victims of circumstance.

To summarize, identity transformations portrayed by respondents are best understood in terms of 'work'. This process of 'becoming other' entails active engagement, intentionality, self-reflection, and effort. The trigger for identity work was the crisis of major illness. Attempts to come to terms with significant losses and to cast their stories in terms of opportunity were part of this work. Respondents went to considerable lengths to demonstrate their moral agency in the face of the ordeal of illness.

Vocational work

Respondents also recounted their experiences of working to re-establish their vocational lives. Half of respondents (7/14) returned to their premorbid vocational pursuits, while the other half was forced to change vocational direction. Regardless of whether vocational status changed or not, all respondents told how their *relationships* to vocation were profoundly changed in the wake of illness. They re-entered the vocational sphere different than when they left it.

Participants portrayed a complex process, whereby 'returning to work' (in the traditional sense) was closely interconnected with other aspects of their lives: for example, availability of spousal or parental support (including financial), possession of disability and unemployment benefits, entitlements to sick leave from employment/training/educational programs, and possibilities for job accommodations. Interwoven with these considerations were their accounts of their altered bodies and 'readiness to return', their transformed identities, their changed relationships to vocation, and the importance of 'being a hard worker'.

All respondents expressed a strong desire to resume vocational pursuits. However, regardless of whether they returned to their premorbid roles or not, the journey back to the vocational sphere invariably was characterized as hard work. Respondents recounted how their experiences of their altered bodies informed their decisions to resume vocational duties. For example, Derek described recognizing that he was ready to resume physically demanding labour. At first, he did not feel ready because:

...I still wasn't at a point where I was 100% trusting of my leg. It just took me a while to get to the point where I knew what I can do with it. And once I hit that point it was just kinda smooth sailing I guess. But it was just trying to find that trust...

While financial pressures were a major concern for Derek, he characterized his bodily experience as being paramount to his readiness to RTW.

While Derek's work (both pre- and post-diagnosis) was physically demanding, those engaged in sedentary jobs also expressed readiness to return in bodily terms. Vanessa, who had a relatively sedentary premorbid vocational role, remarked that not only her own perceptions of her body (and its capabilities), but also the perceptions of others affected her sense of 'readiness' to return to paid work:

I'm afraid to apply for jobs, to be rejected. 'Cause I could send my resume in, and I'm sure I'll get an interview, but I go in there with my crutches or a cane, it's like, even my brother-in-law was saying, "How much work can this person do for me?" (31 at diagnosis, 35 at interview).

She told how her ongoing experiences of fatigue and disability – coupled with the stares and comments of others – reinforced her feelings of 'unreadiness' and limitation.

Respondents drew heavily on discourses of 'work ethics' and went to considerable lengths to portray themselves as 'hard workers'. They constructed accounts to demonstrate

their motivation and commitment to resuming vocational pursuits in some form. However the journey back to the vocational sphere was portrayed as hard work in itself. Carlo (a college student pursuing training in a skilled trade and engaged in a physically demanding part-time work prior to diagnosis) gave a lengthy account of his struggle to RTW. He portrayed himself as stoically dealing with profound disappointment, and compared himself to how others would respond in the same situation. In this excerpt, Carlo uses his story to portray himself as worthy, contrasting his own actions with those of other 'players' in the drama.

I went back to work probably about a year after...[I] asked them if I could have my job back. The human resources guy said, "Yeah, no problem, sure, says to hire you back." So I waited. He's like, "At the end of the week we'll call you." That week passed. Another week passed. I called him up on a Monday morning, left him a voice message. He didn't get back to me. The Friday, I leave another voice message....And they never got back to me whatsoever.

And then I eventually just walked in there one day. He turned around, and he was shocked that I was actually coming there ... He told me to go downstairs to talk to the nurse, 'cause he couldn't tell me whatever he had to say, he didn't even know how to handle it. But basically, they weren't going to give me my old job because I – they weren't even going to find me another job within the company sitting down ... I was trying to get a job everywhere. I had resumes everywhere. And I finally went back to the place that I didn't want to go because I couldn't do it ... But you know, I would have done it no matter what ... But how did I feel? I was disappointed, I was a little upset. But another person I could see, it would absolutely destroy them. But I was all right with it (22 at diagnosis, 27 at interview).

In this detailed account, Carlo not only relates the trials of returning to the workplace, but also performs identity work. He portrays himself as highly motivated and resourceful, the other players as disingenuous and cowardly ("he didn't even know how to handle it"). He depicts himself as strong emotionally, tough physically, hard working. His account is one of banging on the workplace door, demanding to be let back in. He recounts being willing to put his altered body at risk in the name of going back to work.

Respondents recounted a changed relationship with vocation, an experience of 'vocational otherness' in the wake of illness. For respondents like Derek and David, who were forced to abandon their premorbid vocational plans, the changed nature of their vocational lives was particularly pronounced. However, even respondents who ostensibly returned to their premorbid vocational statuses told of changed perspectives on work. Labib (a student before and after illness) commented that his perspective on his career and its role in his life was completely transformed following illness. Previously highly driven and enthusiastic about his studies, he suggests that now work is more a place where he bides his time. On the surface, little would appear to have changed vocationally for Labib, yet he

recounts profound changes wrought by his illness experience and his sense of 'becoming other' to his previous vocational self. Sophia, a professional, told of an all-consuming work life prior to illness, while currently she describes having stepped away from a "24/7" mentality, that she is much more focused on family, friends, and leisure pursuits. She still enjoys her job, but it is no longer the focus of her life. Josh, a student before and after illness, recounts what amounts to a corollary of Labib's experience, that his relationship to vocation changed, but instead of being less motivated to succeed, he has become "passionate" about doing something "big" and important with his life. Regardless of 'vocational trajectory' in the wake of osteosarcoma illness the participants told of lasting effects and new perspectives on vocation.

Respondents, through their accounts of vocational work, attested to a highly complex experience of returning to the vocational sphere. The interconnectedness of physical, social and psychological readiness for vocational work (and perceptions of self and others), societal expectations/discourses (e.g. work ethics), changed perspectives, and the social relations of work were all integral to 'RTW'.

Linking the three types of work

By dividing the accounts of respondents into three separate sections (reflecting three types of work), it may falsely appear that these are three distinct experiences. Instead, respondents' accounts of vocational experiences were intimately connected to their depictions of illness and illness work, and also were closely bound to notions of identity and self-definition. While 'becoming other' was most obviously linked to identity transformations depicted, the language of 'becoming other' also pervaded respondents' accounts of illness and vocation. They described their altered bodies (and the transformations wrought by illness) as well as their changed relationships to vocation.

For example, in Carlo's previous quotation he depicts not only his struggle to resume his vocation, but also performs identity work. Later in his interview, he noted that he was so successful at illness work that he learned to walk without a cane quickly and became adept at masking his disability – to the extent that this ultimately cost him his job when his employer made him redundant in order to hire a 'disabled' person to replace him.

Respondents told how their vocational landscapes were irrevocably changed by their illness experiences. We propose that for significant numbers of osteosarcoma survivors, 're-entry' is a more appropriate conceptualization than 'return'. The respondents re-entered the vocational sphere positioned differently (socially, psychologically and physically) than prior to illness. In their accounts, this re-positioning was intricately interwoven with identity transformations prompted by illness and illness work.

Discussion

In this study, respondents recounted that the onset of osteosarcoma initiated important illness work and identity work. Through identity work, their relationships to

vocation were profoundly changed. Rather than 'going back' to where they left off at diagnosis, respondents told of re-entering the vocational sphere at a different vantage point from which they left. Demographic factors such as gender, age-at-diagnosis, marital and parental status, etc. did not emerge as influential in mediating these experiences.

By re-conceptualizing 'work' and 'RTW' we are challenging prevailing notions of what constitutes 'successful RTW'. The 'work' depicted went far beyond conventional notions of vocational pursuits, and respondents recounted working hard in numerous ways. 'Successful RTW' is usually conceived of in the literature (and in practice/policy) as re-establishment of the pre-illness status quo. These respondents spoke to a far more complex and transformative experience. Such findings have important implications for clinician-patient interactions and for RTW practice and policy. It is these implications to which we now turn.

When patients return for surgical follow up, clinicians frequently ask, "So, are you back to work yet?" expecting simple 'yes-no' answers. Based on our collective clinical experiences, patients typically oblige, offering monosyllabic answers. Our findings indicate that the stories underlying such interchanges are in fact highly complex. The collective 'response' from these participants would be, "Can't you see? I'm *already* working and have been since this ordeal began!"

These findings suggest that practitioners may wish to develop more sophisticated questions, and listen *with* stories, as Frank (2004) proposes: listening for signs of distress or empowerment – for what patients are choosing *not* to say – and acknowledging the transformative nature of the illness experience. Our results indicate that patients do not necessarily 'pick up where they left off', but that their perspectives, goals, and relationships to vocation – and their capacities to undertake certain types of vocational work – may be profoundly changed following such experiences. These results can inform clinical practice by helping clinicians listen differently to patients' accounts (recognizing their complex, nuanced nature) and ask better questions – questions tailored to individuals' circumstances. As Frank asserts, a more dialogic approach (implying reciprocity and openness) to clinical encounters can result in enhanced therapeutic relationships, more mutually satisfying to both patients and clinicians (Frank, 2004).

While we have depicted respondents' accounts as being about three different forms of work, we are not the first authors to characterize illness in terms of 'work'. Corbin and Strauss (1988) depicted management of chronic illness (by patients, spouses) in terms of 'work': that of managing the effects of disease, of maintaining activities of daily living, the emotional work necessitated by disrupted goals and plans, and the division of labour among couples. Their focus was overwhelmingly on *tasks* related to illness management. While respondents in our study spoke of tasks performed, they never suggested that others undertook this work. They portrayed illness work as an individual pursuit, one that ultimately they alone were able to perform. They noted the importance of support, yet chose

to emphasize their own agency in managing their ordeals. Illness work is about not only managing corporeal symptoms and emotional reactions to the altered body, but is also about complex relational work engaged in by participants. Respondents in this study spoke to more than a division of labour between two parties, instead recounting active negotiations within a broader social landscape.

Herzlich and Pierret (1987) characterized the "job of being sick" in active terms, but chose to emphasize a struggle *against* illness. In contrast, respondents in our study tended to couch their experiences in terms of actively engaging *with* illness and *incorporating* it into their lives. While the work of preserving one's identity "intact" was depicted by Herzlich and Pierret (1987), this study has emphasized identity *transformations* in the face of illness. Although the respondents in our study spoke of preserving some elements of identity, they chose to emphasize the profound changes undergone. Rather than fighting and refusing to 'give in' to illness, they highlighted active acceptance.

We are not the first authors to use the term 'identity work'. In a study of childhood cancer, Drew (2003) also used this term to describe her participants' "efforts at biographical revisioning and self-reconstruction" (Drew, 2003: 183). She too uses the notion of 'becoming other' along Frank's (2001) lines, indicating that this process entails both moral agency and active negotiation (Drew, 2003; Frank, 1995). Like Drew, we found that the cancer experience had profound effects for these individuals long after the episode of acute illness had passed (Drew, 2003) – be it from ongoing bodily reminders (scars, disability), identity shifts, or embarking on new vocational paths.

Re-conceptualizing work and RTW as we have done holds implications for researchers, practitioners, and policy makers. By problematizing what constitutes a 'successful' RTW outcome, this study suggests that we need new ways of defining and 'measuring' such outcomes. Indeed researchers may wish to focus more on the *process* of RTW than they have done to date.

Practitioners and policy makers may want to reconsider current conceptualizations of vocational rehabilitation. For many individuals, returning to premorbid pursuits may not be a viable option, and they may need time and assistance to carve out new vocational paths. Moreover, the loss of valued vocational pursuits can have important implications for identity (in terms of role definition, social relations, sense of purpose and self-worth); hence, embarking on a new vocational path is much more complex than 'finding a new job'.

Even when they did return to their premorbid pursuits, respondents in this study indicated that their relationships to vocation were changed in the wake of illness. They may have ostensibly 'gone back', but remarked that their attitudes, goals and motivations, and even the importance of vocation in their lives, were drastically altered by their experiences of illness. Acknowledgement of this changed relationship to vocation by practitioners, employers, educators, insurers and policy makers may help them to address patients' needs more effectively. For example, clinicians may wish to tailor vocational rehabilitation programs to patients' new goals. Employers, disability

insurers and educators may wish to offer greater flexibility to support individuals experiencing illnesses like osteosarcoma as they re-enter the vocational arena (providing sufficient time to engage in the work of recovery, embark on new vocational paths, acquire appropriate training, etc.). All respondents in this study expressed a desire to make a meaningful social contribution, regardless of their vocational status or the relative disruption to their work life trajectory.

Respondents spoke of a disconnect between workplace practices and policies. They told how workplace/institutional accommodations were advocated at the level of policy, but that in practice, proffered accommodations were not always forthcoming. Respondents recounted struggling to wrestle accommodations from employers and institutions of study/training. This suggests that greater attention may need to be targeted toward the implementation/enactment of accommodations at organizational/institutional levels. Moreover, the possibility of accommodations was often premised on self-identification as 'disabled', a label most respondents eschewed. Respondents spoke instead of 'limitations' experienced and of 'doing things differently' than before. Self-identification as 'disabled' should not be a pre-requisite for assistance or accommodation, although this is frequently the assumption underlying many RTW policies (Pelkowski & Berger, 2003; Sim, 1999). The burden of self-advocacy demanded by current practices of workplace/educational accommodation is yet further work that institutions sometimes impose on people experiencing the sequelae of illness. This is but one example of the intersection of identity work and vocational re-entry.

A few recent qualitative investigations with HIV and mental health populations have begun to characterize the complex interrelationship between chronic major illness and RTW. This relatively small body of literature highlights the intricate intersection between issues of living with a future characterized by uncertainty (similar to respondents in our study), crises of identity engendered by illness, as well as structural factors (e.g. access to disability/drug benefits, workplace organization, ease of changing vocational pathway) (Alexis & Lucca, 2002; Ezzy, 2000; Ferrier & Lavis, 2003; Millward, Lutte, & Purvis, 2005; Nixon & Renwick, 2003). In a similar vein, our study reflects the extraordinary complexity of the experience of vocational resumption in the wake of life-threatening illness.

Conclusions

This study explored accounts of three different types of 'work' engaged in by respondents following diagnosis with osteosarcoma and offers a re-conceptualization of certain types of 'work', as well as what it means to 'RTW'. It offers a way of interlinking these three types of work in a novel and coherent framework. Respondents depicted illness as a crisis that entailed not only illness work, but also triggered important identity work. Identity work was portrayed as a transformative process, one of 'becoming other' to who they had been prior to illness. As a result, respondents told of re-entering the vocational sphere different than when they left it.

This research holds important implications for both clinician–patient interactions and the broader arena of RTW practice and policy. Clinicians, employers and policy-makers may wish to acknowledge that survivors do not 'pick up where they left off', but are changed in the wake of their experiences. Such changes have implications for survivors' vocational goals, and their relationships to vocation. These findings could help clinicians adopt a more sophisticated and nuanced approach to issues of RTW with their patients. They could also help employers and policy-makers design RTW programs and policies that are tailored to individual needs, based on the recognition that cancer patients have been working hard in multiple ways before they even consider re-entering the vocational sphere.

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