



## “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,

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