



## Overview

# Issues of Survivorship and Rehabilitation in Soft Tissue Sarcoma



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Received 30 March 2017; accepted 5 April 2017

## Abstract

As the number of survivors of extremity soft tissue sarcoma increases, so does the need to understand the experience of survivors and develop measures, systems and services that support rehabilitation into normal life roles. Survivorship includes considerations of the physical, psychological and social domains, of which the physical sequelae of treatment are the best characterised in the literature. The survivorship experience may include disability, pain, lymphoedema, psychological problems, as well as difficulty with employment, relationships and lower quality of life. Rehabilitation strategies for extremity sarcoma patients must be personalised, holistic and begin early in the pathway, ideally before the first treatment intervention. The International Classification of Functioning, Disability and Health model is a useful framework for combining assessments, including objective outcome measures, which can be combined into a rehabilitation prescription. Research is needed to develop an evidence base for rehabilitation interventions to support patients with extremity soft tissue sarcoma. © 2017 Published by Elsevier Ltd on behalf of The Royal College of Radiologists.

**Key words:** Disability; impairment; rehabilitation; sarcoma; survivorship

## Statement of Search Strategies Used and Sources of Information

During the research for this article the authors used the following search terms: survivorship, rehabilitation, sarcoma, impairment and disability.

## Introduction

Sarcomas originate in connective tissues and other supportive structures such as bone, muscle and blood vessels. It is no surprise, therefore, that sarcoma treatment involving the removal of muscle and bone can have a dramatic impact on the locomotor system, routinely causing impairments, disability and restricting participation in normal life. Although the incidence of soft tissue sarcoma increases with age, many patients are young, increasing the burden over time on patients, their families and society. Incremental improvements in survival mean that there are an estimated

280 000 sarcoma survivors in Europe [1,2]. Patients have a wide range of survivorship experiences and require tailored specialist treatment, information and support.

This overview explores the survivorship experiences of patients treated for an extremity soft tissue sarcoma, the provision of rehabilitation services and discusses future directions. Some aspects may be relevant to patients with soft tissue sarcomas in other locations and some relevant studies from patients with bone sarcoma are included, but their detailed description is beyond the scope of this review.

## What is Survivorship?

Survivorship is the lived experience of individuals after treatment for cancer. The term encompasses the physical, psychosocial and economic sequelae of cancer diagnosis and treatment in paediatric and adult survivors of cancer [3]. The recognised domains of survivorship are: pain; sexual function; cognitive functioning; employment, finance and return to work; emotional distress; depression; anxiety; and social needs. Here these are considered in three sections: physical (fatigue, physical functioning and pain); psychological (emotional distress, cognitive functioning, depression and

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anxiety); and social (sexual function, employment and social needs) [4].

### Physical

Treatment for extremity sarcoma often leads to disability and participation restrictions, particularly after lower extremity tumours [4–8]. Physical functioning may worsen during treatment and then improve for a year or more, before plateauing [9,10]. In the longer term, patients may remain less active than controls [11]. High-grade, large size tumours, resection of motor nerves and flap reconstruction are all associated with poorer outcomes, the latter possibly because tumours are often larger and need radiotherapy [12,13].

Treatment leads to structural impairments (e.g. reduced joint movement), activity (walking, dressing) and participation restrictions (e.g. sports or employment). These are interdependent, for example higher physical impairment is associated with lower health related quality of life (QoL) [14–17]. Evaluating and understanding these different aspects requires standardised outcome measures and cohorts of patients [18].

Maintaining physical activity levels after cancer treatment is important, not only to improve general health but reduced physical activity may be linked with lower survival rates (e.g. after breast, colon or colorectal cancer) [19]. Therefore, patients treated for extremity soft tissue sarcoma may be at further increased risk of poor cancer outcomes. Furthermore, regular exercise may help to improve the lower exercise capacity (including  $VO_{2max}$ ) seen in some survivors of paediatric cancer [20].

### Amputation or Limb Salvage?

Most patients with extremity soft tissue sarcoma have limb-sparing surgery, but some undergo amputation. Survivorship experiences may differ, although QoL is similar after both [21]. Although amputation is associated with more disability, some patients have poor physical functioning after limb-sparing surgery and others function very well after amputation (particularly at the trans-tibial level) [17], but the latter depends on good limb fitting services, which vary widely in the National Health Service [22].

Both groups may experience pain and rehabilitation can be prolonged. Falls are also common after amputation (62% report falls) and limb-sparing surgery, for example after femoral nerve resection [17,22,23]. Falls cause fractures and other injuries, hence strategies to prevent and manage falls are important [22].

Decisions about limb-sparing surgery or amputation should consider the trade-offs between the two approaches. Publicity around paralympians in particular may be changing attitudes to disability and may lead to a greater acceptance of amputation [24].

### Fatigue

Fatigue includes problems with concentration, motivation and physical activity, and affects people with several cancer

types, including sarcoma, particularly during treatment [10]. Twenty-eight per cent of patients with benign or malignant bone and soft tissue tumours report severe fatigue, associated with treatment complications, less optimism and somatisation [25]. Fatigue is also associated with pain, anxiety and low self-efficacy [26]. Amputees may report less fatigue; it has been suggested that this is because the physical changes after treatment have to be accepted [27].

### Pain

Pain is common in survivors, regardless of local treatment [21,28,29]. Pain is a regular feature in over 90% of patients after amputation (severe in 9.5%) [17] and has a significant and negative impact on physical functioning, QoL and employment. Although pain may improve from the diagnostic to treatment phase, it can last for many years [10,17,21,29,30].

### Lymphoedema

The interruption of lymphatic drainage by surgery or radiotherapy makes lymphoedema an expected complication, affecting about a third of patients after extremity soft tissue sarcoma, some severely [31]. Factors associated with lymphoedema include larger (>5 cm), deep tumours and vein resection [32]. The large volume limbs that result are associated with poorer outcomes [33].

### Psychological

Psychological distress is reported by about a third of patients. At diagnosis, anxiety predominates, and a year after treatment, depression is predominant [34]. There is a high rate of anxiety and depression from diagnosis to follow-up [35], which may persist. In one study of paediatric sarcoma survivors, 77% reported long-term psychological distress [36]. Psychological functioning is closely linked to physical functioning and social domains, and access to psychological therapy, support and counselling is important. Body image may change, particularly after amputation, and this has been linked to QoL outcomes [21].

### Social

A sarcoma diagnosis may accentuate social isolation and affect relationships and sexual functioning [37]. Single patients have a higher risk of sarcoma-specific death, possibly because spouses facilitate treatment either financially or through logistical support [38].

Despite poor fitness, adult survivors of childhood extremity sarcoma are as likely to be married, live independently, be employed and attend college as controls [16]. Lack of participation in life roles, marital status, age and professional status predict QoL [10,39]. Psychological distress and pain may be barriers to employment [40,41] and most patients would benefit from vocational counselling [33].

Sarcoma treatment may affect participation in sports, with potential consequences for long-term health and

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