Occupational therapy rehabilitation for sarcoma patients following limb salvage surgery; a scoping review.

Abstract

Introduction

Sarcomas are rare cancers of bone and soft tissue, and limb salvage surgery is the standard treatment followed by multidisciplinary rehabilitation. The scoping review aimed to summarise the evidence for occupational therapy intervention for adult sarcoma patients following limb salvage surgery.

Methods

A review of the literature using a scoping framework was undertaken starting with a systematic database search, followed by an analysis of the literature. The literature was described using a numerical analysis, and the following headings; a) rehabilitation, b) activity limitations and participation restrictions, c) functional outcomes.

Findings

Nineteen articles met the review criteria, papers were diverse in study location, type, population, methods and outcomes used.

Following limb salvage surgery patients experience functional deficits, activity limitations and participation restrictions in life roles and loss of previous identity. Prehabilitation can influence functional outcomes. Functional activity was found to plateau at 4-12 months following limb salvage surgery, with some patients identifying a need for further rehabilitation.

Conclusion

The review identified limited evidence guiding occupational therapy practice for sarcoma patients following limb salvage surgery. Further research is needed to demonstrate the effectiveness of occupational therapy intervention in the early and late stages of rehabilitation and develop evidence based guidelines.

Keywords; Sarcoma, limb salvage, occupational therapy, rehabilitation.

Introduction

Sarcomas are rare cancers that develop in bone or soft tissue and account for approximately 1.3% of all cancers in the United Kingdom [1]. Approximately 45% of people with soft tissue sarcoma and 55% of those with bone sarcoma can expect to survive for more than 10 years [2,3]. It is estimated there are 280,000 sarcoma survivors in Europe [4], and figures reported by the Surveillance, Epidemiology and End Results (SEER) programme [5] providing cancer statistics in the United States, estimates that soft tissue sarcoma and bone and joint cancer will account for 0.8% of all cancer diagnoses in 2019.

The most effective treatment for sarcoma is surgical resection and limb salvage surgery has become the standard management of extremity sarcomas [6] . Limb salvage surgery involves complete resection of the tumour and associated structures and aims for disease free survival whilst maintaining maximum function [7,8]. Although the preservation of function is secondary to survival it is an important consideration in treatment planning [9] and good post-operative rehabilitation will enable patients to reach and maintain their optimum function [10].

Rehabilitation in cancer care aims to restore patients to their former roles and functional ability enabling them to adjust to any limitations [11]. This may also involve supporting them to participate in meaningful activities to achieve optimal health and wellbeing [12]. The World Health Organisation's (WHO) International Classification of Functioning, Disability and Health define activity as "the execution of a task or action by an individual" and participation as "the involvement in a life situation" [13 p.10]. It has been recognised that the rehabilitation burden can be greater for patients following limb salvage surgery than following limb amputation [14]. Following limb salvage surgery patients may experience difficulties resuming activities of daily living, participating in home and community activities and returning to work [15]. However, the aim is to enable them to regain their pre-operative functional levels.

With the development of sub-specialities in therapies, including sarcoma services, there is growing interest in the evidence for the rehabilitation of patients following limb salvage surgery and occupational therapists play a key role in this. "Occupational therapy aims to improve or maintain function in work, leisure, self-care, domestic activities, social roles and psychological status" [16 p. 435]. A preliminary search of the literature for "occupational therapy rehabilitation following limb salvage surgery for sarcoma" identified a lack of evidence. Davis [17], identified that few studies had reported functional outcomes for patients after limb salvage surgery for soft tissue sarcomas. Most available literature focused on impairments such as strength and range of movement rather than activities of daily living, self-care and mobility with little acknowledgment of participation restrictions [17,18]. More recently rehabilitation for sarcoma patients has gained recognition through guidelines for cancer services and health professionals.

The National Institute for Health and Care Excellence (NICE) practice guidelines for sarcoma identified the need for sarcoma patients to have timely access to appropriate support and rehabilitation services, involving occupational therapy and physiotherapy to achieve optimal post-operative function [19]. Achieving World Class Outcomes [10] is a strategy to improve the outcomes for people with cancer by 2020. It makes recommendations for the rehabilitation of people with cancer, placing importance on cancer survivorship and the role of allied health professionals. The Quality Improvement Development and Innovation Scheme project 2012-2013, commissioned by the National Sarcoma Commissioning Group, reviewed rehabilitation services for people with bone sarcoma and developed a model to provide effective and seamless rehabilitation across the UK [15]. Despite this work, guidelines to support occupational therapy practice with sarcoma patients are lacking. This scoping review identifies the evidence for the occupational therapy rehabilitation of sarcoma patients following limb salvage surgery, focusing on activities of daily living, participation in activity, and predictors of functional outcomes.

Methods

The methodology framework for scoping studies as suggested by Arksey and O'Malley [20] was used to guide the process. A scoping review enables the "extent, range and nature of a research activity to be examined" [20 p.6]. It also allows for mapping of the evidence "summarising a range of evidence in order to convey the breadth and depth of a field" [21 p.1] It may be particularly appropriate in disciplines where there is emerging evidence and was used here as there is a dearth of evidence for occupational therapy rehabilitation of sarcoma patients. Five stages in this process have been identified as; (i) identifying the

research question, (ii) identifying relevant studies, (iii) study selection, (iv) charting the data, and (v) collating, summarising and reporting results [20].

1. Identifying the research question.

Key papers identified in the preliminary search published by Davis [17] and Parsons and Davis [18] found a lack of research reporting functional outcomes, participation restrictions and evaluating rehabilitation treatments for soft tissue sarcoma patients. Since the publication of these papers rehabilitation practice has evolved therefore we sought to review all papers since 1999.

The main question guiding the review was; what evidence is available evaluating functional outcomes and occupational therapy rehabilitation in relation to activities of daily living and participation restrictions for sarcoma patients following limb salvage surgery? Function was defined using the World Health Organisations, International Classification of Impairment, Functioning, Disability and Health (which refers to activity and participation when defining function) [13]. The interventions considered were occupational therapy or rehabilitation which considered activity, participation restrictions and functional outcomes. The population included both bone and soft tissue sarcoma patients due to the lack of evidence available for rarer cancers such as sarcoma and the broad nature of the scoping review.

2. Identifying relevant studies.

A literature search was carried out in February 2019 to identify relevant papers. A combination of key words and MeSH terms were used as shown in table 1. The following electronic bibliographic databases were selected; Cumulative Index to Nursing and Allied

Health Literature (CINAHL), Medline, Allied and Complementary Medicine Database (AMED) and Excerpta Medica Database (Embase). The PubMed database was not searched, as the option for ahead of print citations preceding final publication in Medline was used, therefore PubMed was unlikely to identify any further articles. Additionally, the Google scholar search engine was accessed but did not identify any additional papers. The search strategy was initially created in Medline and then translated onto Amed, Embase and Cinahl and was reviewed by an independent librarian.

(Table 1 to be inserted near here)

Once key papers had been identified the reference lists of these papers were crosschecked and 2 further papers that met the inclusion criteria were identified. Date limitations were applied and only articles published since the paper by Davis in 1999 [17] were included.

3. Study selection.

The preliminary search identified many papers comparing surgical technique and using functional outcome measures without evaluating rehabilitation. In order to eliminate studies that did not address the research question inclusion and exclusion criteria were applied to focus the search.

Inclusion criteria;

- Primary and secondary research articles of patients with bone and soft tissue sarcomas.
- Studies evaluating rehabilitation
- Studies that considered activities of daily living and participation.
- Studies with or without a comparator.
- English language and peer reviewed papers.

Exclusion criteria;

- Paediatric studies with a study population of less than 25% of patients over 16 years, to capture evidence relating to adolescents and adults.
- Studies older than 1999
- Case reports, conference and opinion papers.
- Studies that reported functional outcomes only with no evaluation of activities of daily living or participation in activity.
- Articles that focused solely on quality of life or end of life care.

The titles and abstracts of identified papers were screened based on the inclusion criteria to identify those for full review. If the reviewer was unable to determine if an article met the criteria based on the title and abstract alone the full article was reviewed.

Figure 1 summarises the search. We identified 1394 papers through the database search, 2 hand searched articles were reviewed in full and met the inclusion criteria. We excluded 1272 based on title and abstract alone and removed 21 duplicates. The 103 remaining papers were reviewed in full; a further 86 were excluded based on the inclusion criteria leaving 17 papers to include in the review.

(Figure 1 to be inserted close to here)

4. Charting the data

This stage involved charting items of information according to key issues and relevance to occupational therapy rehabilitation. A data extraction form was used to evaluate papers in

detail; key data was extracted e.g. study type, aims, sample size, study population, age range and a summary of the method, results and limitations. Data was extracted by one researcher and reviewed by a second researcher.

5. Collating, summarising and reporting results.

A scoping study provides an overview and descriptive account of the literature but does not synthesise the evidence. It is suggested that a scoping review requires an analytical framework or thematic analysis in order to present a narrative account [20]. A basic numerical analysis of the 17 papers included was used to identify year of publication, study location, study design, population and age range of participants (table 2). Papers that met the inclusion criteria were reviewed and relevant headings identified and used to structure the results. The following topics were deemed as relevant to occupational therapy rehabilitation; a) rehabilitation, b) activity limitations and participation restrictions and c) functional outcomes. These were used to structure the evidence.

(Table 2 to be inserted near to here)

Results

Numerical analysis

Papers published since 1999 were considered for the review and included 2 papers published in the last 2 years demonstrating the interest of this topic and the evidence emerging to the profession. Study location was varied with the majority of papers published in the United States, Canada and the United Kingdom. Of the 17 papers included in the review 3 were literature reviews [8,14,17], 1 was a mixed method study [22], 6 were retrospective cohort studies [23–28], 1 was a case control study [29], 4 were cross sectional studies [7,15,30,31], 2

qualitative studies [32,33]. Study populations were heterogenic and 3 studies included patients with a variety of cancers including sarcoma [22,26,28], 1 with both primary bone and soft tissue sarcomas [30], 7 with 100% soft tissue sarcoma patients [7,8,14,17,24,27,29] and 6 studies with 100% primary bone sarcoma patients [15,23,25,31–33]. The age of study populations also varied with 5 studies reporting the results of adolescents and adults under the age of 35 years.

a) Rehabilitation

Rehabilitation is key to enabling good post-operative functional outcomes for sarcoma patients following limb salvage surgery. It should occur pre-operatively, during hospital admission and postoperatively in the community, in out-patient clinics or on readmission. The review endorsed that "prehabilitation" should begin early following a sarcoma diagnosis and can be described as an assessment of medical status, comorbidities, physical problems, and baseline function. It is suggested an understanding of pre-treatment function, tolerance to activities of daily living, the home environment, care support, pre-existing independence, vocational status, return to work and financial concerns is required at an early stage in the process [8,14]. The preoperative expectations of soft tissue sarcoma patients were found to significantly predict post-operative function and patients who had uncertain expectations about recovery had worse functional outcomes than those who anticipated an easy recovery [24].

Enhanced recovery protocols were advocated for soft tissue sarcoma patients as it was shown to be possible to reduce the length of stay without compromising surgical or oncological outcomes, re-admission rates or morbidity [8,29]. In general, there was a lack of evidence

describing rehabilitation interventions and protocols [8,25]. A standardised post-operative protocol focusing on mobility and transfers resulted in improved functional outcome scores in those with primary bone sarcoma [25]. However, the importance of individualised patient centred goals has also been acknowledged based on changes in functional outcome and was particularly beneficial for adolescents and young adults [15,22]. Furthermore patients who have a good understanding of their prognosis were found to be better able to set rehabilitation goals [28]. The International Classification of Functioning Disability and Health model [13] may be a useful tool for evaluating and formulating rehabilitation treatments and plans that acknowledge a combination of assessments and outcome measures for soft tissue sarcoma patients [8]. Hudson et al [15] proposed a model for post-operative rehabilitation of bone sarcoma patients to maximise outcome and patient satisfaction. It involves telephone consultations and clinical review at 6 weeks post-surgery, rehabilitation admissions at 3 and 9 months and a wellbeing day on completion of treatment. The benefit of wellbeing days has been recognised in the literature suggesting this encourages patients to share their experiences with others who underwent similar treatments, provides self-management advice and rehabilitation information. Wellbeing days should include physiotherapy, occupational therapy, pain management, benefits advice and psychotherapy [8].

Sarcoma patients may experience challenges engaging in rehabilitation due to multiple co-morbidities [28]. Two studies reported patients unmet rehabilitation needs and noted that additional rehabilitation would have been beneficial [15,26]. In a review of rehabilitation provision at specialist sarcoma units over 60% of upper and lower limb patients stated they would have benefited from an early or late rehabilitation admission but formal out-patient review by health professionals was found to be lacking. Analysis of subgroups based on surgical procedure found that more upper limb than lower limb patients reported that they had

received enough rehabilitation. Only 48% of lower limb patients, including pelvic resections, reported they had received enough rehabilitation and activity limitations due to joint stiffness were highlighted by patients with distal femoral and proximal tibial replacements [15]. Unmet rehabilitation needs were particularly apparent in young non-white adult men ,and those with physical health and emotional problems but less apparent for patients currently receiving treatment due to frequent interactions with healthcare professionals [26].

b) Activity limitations and participation restrictions.

Patients with extremity sarcomas experience impairments, activity limitations and participation restrictions following treatment, some also identified a loss of future opportunities and previous identity and role [17,27,32]. In a long term study on the late effects of treatments for bone sarcoma of the hip and pelvis, participants identified that functional impairments caused practical difficulties and a loss of their previous identity such as being unable to engage in previous sporting activities and felt labelled by their disease [32]. Interruption to their vocation was found to last 1 year or more and 3 types of work were identified; illness work, identity work and vocational work, [33].

Davis [17] found that patients have significant impairments following sarcoma treatment and suggested that most studies up to 1999 focused on impairments rather than the effect on activities of daily living, and participation in vocational roles was not recognised. Since 1999, there has been some recognition that limb salvage patients experience participation restrictions and activity limitations following limb salvage surgery. Reduced participation in work, sports and social activities and negative changes such as requiring mobility aids, difficulties with stairs, public transport and carrying out household tasks were identified [32]. Participation restrictions such as an inability to return to work, resuming previous roles, care

within the family and recreation activities were found to have a greater importance than performing activities of daily living and mobility as patients reported they had more impact on their quality of life [27].

c) Functional Outcomes

Davis [17] recognised that studies before 1999 lacked standardisation of outcome measures and identified a need for valid and reliable functional outcomes. The Musculoskeletal Tumour Society Rating Scale (MSTS) and the Toronto Extremity Salvage Score (TESS) were most frequently used to measure functional outcome in the papers included in this review. Baseline activity was found to be a significant predictor of post-operative TESS scores [24]. The initial post-operative TESS score was also a predictor of overall function at a year or more with lower limb patients demonstrating lower scores [7].

Lower TESS scores indicate a greater extent of physical disability and may be more apparent in upper limb patients due to the functional complexity of these tasks. TESS scores were significantly different between minor and major upper limb surgery groups ($p=0.0001$) but no difference was found in the lower limb groups as their activities of daily living are potentially less functionally complex [15]. Findings suggested that patients with distal femoral, proximal tibial endo-prosthetic reconstructions and pelvic resections experience greater activity limitations and disability, and therefore may have increased rehabilitation needs. Following endoprosthetic reconstruction of the knee many had mild impairment scores with an overall TESS score of 86%, their most significant difficulties were in kneeling, participating in sports and walking upstairs and up/down hills [15,23]. Functional ability plateaued at 4-8 months following limb salvage surgery for bone sarcoma, but after pelvic resections it continued to improve for up to 12 months [25].

The Assessment of Motor and Process Skills (AMPS) and the Canadian Occupational Performance Measure (COPM) were used in 3 studies included in the review. Adults who received treatment for childhood sarcomas demonstrated significantly lower activity of daily living motor and processing ability than the age matched group [30,31]. The COPM was used to measure the participation of young adults with cancer in goal orientated rehabilitation programmes, and found an increase in participation and a significant change in performance and satisfaction at the end of the programme. However, only 6% of this group had a sarcoma diagnosis [22].

Discussion

The aim of this scoping review was to summarise the literature, from 1999 onwards, evaluating functional outcomes and occupational therapy rehabilitation in relation to activity and participation for sarcoma patients following limb salvage surgery. Only 17 papers over this period met the inclusion criteria and therapeutic interventions were generally not well described. Papers were diverse in study location with the majority from the United States, Canada or the United Kingdom. The study type, population, methods and outcomes used were also diverse. Although participants in all studies had undergone limb salvage surgery, anatomical site varied and only one study looked at patients who had limb salvage surgery and reconstruction at a single anatomical site [23,31]. The diversity of papers made synthesis of results difficult and there were more studies of patients with soft tissue sarcoma. This may have been due to the rarity of bone sarcomas limiting the potential for research.

The importance of rehabilitation for sarcoma patients following limb salvage surgery was recognised as it enables patients to regain function and adjust to their limitations [11,14]. The review found that prehabilitation (rehabilitation before surgery) and early intervention, including baseline function, exercise and activity tolerance is required as this influences

functional outcomes [8,14] Further research is required in this area but occupational therapists can play a key role in pre-treatment intervention. Cancer prehabilitation also has the potential to reduce health care costs by reducing complications and readmissions following surgery and treatment [34]. This may be unsurprising as early intervention and enhanced recovery protocols in orthopaedics are well established. Managing the expectations of patients and their families [8] along with patient education has been found to influence post-operative outcomes [24]. Pre-operative education can empower patients and this is a key component of the occupational therapy process [35]. Empowerment and prehabilitation may be essential for sarcoma patients to enable them to effectively prepare for surgery and subsequent rehabilitation. However, it should be recognised that this may be challenging when surgical outcomes are unclear pre-operatively and oncological treatments may delay rehabilitation [9].

The assessment of functional outcomes is important in establishing patients' baseline function, and reviewing rehabilitation goals. The only sarcoma specific outcome measures available and used in the literature were the Musculoskeletal Tumour Society Rating Score (MSTS) and Toronto Extremity Salvage Score (TESS). Patients' experience of their treatment is an important quality indicator in healthcare and patient-reported outcome measures such as the TESS enable clinicians to gain an insight into the way patients perceive their health and the impact that treatments have on their quality of life [36]. The TESS may also be used to predict functional outcomes [7] and identify rehabilitation needs in the post-operative phase [37]. It is reported to be a reliable, valid and responsive measure of physical function in patients with extremity sarcomas, but it can be argued the TESS does not identify psychosocial needs. The MSTS was developed as a standard rating scale to compare the results of limb salvage surgery and amputation for extremity sarcoma [38]. The reliability, validity and responsiveness of the MSTS is unknown and it only provides a clinician with

measurements of impairment at the joint. Measures such as the TESS and MSTS do not provide a complete picture of an individual's impairment, disability or activity restrictions. Therefore, the need for objective assessments of function have been recognised, to improve clinicians understanding of patients overall ability. There is emerging evidence regarding the objective measurement of physical components such as gait and physical activity [39] but evidence for such measures in occupational therapy practice with sarcoma patients is still lacking. Two generic outcome measures were used in the literature, the Assessment of Motor and Process Skills (AMPS) an objective measure which assesses the quality of a person's activities of daily living [30,31], and the Canadian Occupational Performance Measure (COPM); a client centred measure which focuses on the areas of self-care, productivity and leisure [40]. However, sarcoma specific objective measures as well as patient reported outcome measures of occupational performance and function that are sensitive to physical and psychosocial aspects are required to support clinical practice.

Rehabilitation for sarcoma patients commonly occurs in orthopaedic settings and findings from joint arthroplasty literature suggest that return to participation in occupational roles should be addressed early in the post-operative recovery period, as participation restrictions are increasingly important to patients [41]. Sarcoma patients experience participation restrictions and limitations re-engaging in activity [27,32] and participation in previous activities and life events was identified as important to their quality of life following limb salvage surgery. Rehabilitation programmes should therefore aim to increase patient's participation in previous roles and enable them to create new identities as this may have a significant impact on their quality of life. The literature also identified reduced ADL (activity of daily living) motor and processing skills, resulting in difficulties carrying out activities, this may particularly pertinent to survivors of childhood sarcoma [30,31]. As there

is limited evidence regarding activity limitations and participation restrictions for patient's following limb salvage, clinicians are required to extrapolate findings from cancer literature generally to provide an evidence base for their interventions [18].

Few studies have addressed vocation and return to work [22,27] but one paper identified only 50% of soft tissue sarcoma patients were able to return to their previous vocations [17]. Return to work activities should be addressed following the acute phase when a focus on role development and vocation is beneficial [8]. Enabling patients to return to work is an essential part of the rehabilitation process, and a primary goal of occupational therapy is to enable patients to participate in activities of daily living including vocational activities [42]. Vocational rehabilitation enables the person to overcome barriers to accessing, remaining or returning to work after illness, injury or impairment. Although it is acknowledged the evidence for occupational therapy in vocational rehabilitation is generally lacking, occupational therapy has been found to have a positive effect on return to work programmes [16,42]. Hudson et al [15] suggested patients may benefit from out-patient follow up and rehabilitation admissions within the first year following limb salvage surgery, which may provide opportunity for clinicians to address barriers for return to work and provide vocational rehabilitation. Enhanced recovery protocols are frequently applied in orthopaedic settings where the rehabilitation focus is on meeting the goals for hospital discharge. When these principles are applied to sarcoma patients they were found to reduce the length of stay when compared to standard care [29]. In these settings rehabilitation admissions and late rehabilitation may be beneficial to enabling sarcoma patients to maximise their rehabilitation potential, avoid functional plateauing and address return to work activities.

Functional activity was also found to plateau at 4-12months post operatively suggesting there is a period of time following discharge from hospital when patients may benefit from further rehabilitation to maximise their functional independence. Over 60% of upper and lower limb bone sarcoma patients reported they would have benefited from further rehabilitation at 3 or 6 months post discharge [15]. This may be particularly valuable for specific groups of patients such as those with distal femoral or proximal tibial endo-prosthetic reconstruction and pelvic resections who were found to have greater activity limitations [15,23].

Fewer unmet rehabilitation needs were identified by participant's who were undergoing treatment [26] than those who had completed their treatment. This may be due to the primary goal of surgery being curative, with functional outcomes being secondary. Patients may not prioritise this if they have support in the short term following treatment, but in the longer term regaining pre-treatment levels of function and identity and participating in activities has been found to have significant impact of their quality of life [32]. Despite unmet rehabilitation needs being identified for sarcoma patients, few sarcoma units provide formal out-patient rehabilitation [15]. Post-operative and late rehabilitation review in out-patient settings may provide the opportunity for cancer rehabilitation to be fully integrated into the sarcoma care pathway.

Early literature [18] suggested studies evaluating rehabilitation interventions and standard rehabilitation protocols for sarcoma patients were lacking. The review found that despite recent work by Gerrand and Furtado [8], Saebye et al [7], Tobias and Gillis [14], Michot et al [29], Hudson et al [15] and Fauske et al [32] and the recommended multi-disciplinary approach to sarcoma care [19] this area is still significantly under investigated. The authors recognise a limitation of this review was that only papers published in the English language were included, this was due to translation costs but inclusion of papers in languages other than English may have identified a wider breadth of evidence.

Conclusion

This scoping review identified a dearth of evidence for the occupational therapy rehabilitation of sarcoma patients following limb salvage surgery and provides a basis for future studies focusing on this topic. The available evidence suggests that sarcoma patients experience functional deficits, activity limitations, participation restriction in life roles and loss of previous identity following limb salvage surgery. Functional ability was found to plateau between 4-12 months with some groups of patients not maximising their rehabilitation potential or identifying that they would have benefitted from further rehabilitation. The review highlights the key areas for occupational therapy rehabilitation during the prehabilitation, acute and late rehabilitation stages. Further research is needed to demonstrate the effectiveness of rehabilitation guidelines and further develop the evidence base to support occupational therapy interventions for sarcoma patients.

(word count 4650)

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Table 1: Search terms.

Table 2: Overview of studies.

Figure 1; PRISMA flow diagram [43]

Table 1 – Search terms for database search.

Database	Search term
MEDLINE, AMED, CINAHL, EMBASE	(Sarcoma MH or sarcoma.ti,ab.) AND (Rehabilitation or rehabilitation.ti,ab.) OR (Sarcoma MH or sarcoma.ti,ab.) AND (Occupational therapy MH or occupational therap*ti,ab.) OR (Sarcoma MH or sarcoma.ti,ab.) AND (activit* of daily living.ti, ab) OR (Sarcoma MH or sarcoma.ti,ab.) (Sarcoma MH or sarcoma.ti,ab.) AND (Rehabilitation or rehabilitation.ti,ab.) AND (function* or outcome*.ti,ab.) OR (Sarcoma MH or sarcoma.ti,ab.) AND (Participation or participation.ti,ab.)
GOOGLE SCHOLOR	Rehabilitation and sarcoma.

Table 2 – Overview of studies included.

Author and date of publication.	Type of study	Aim.	Number of participants/ sarcoma diagnosis.	Age range	Key findings	Limitations
1. Gerber et al [30] UNITED STATES OF AMERICA	Cross sectional study.	To evaluate function and performance in adult survivors of childhood and adolescent sarcomas. To describe the inter-relationships among impairments, performance, and disabilities in survivors of pediatric sarcoma and identify measures that profile survivors at risk for functional loss.	32 Diagnosis; Ewings sarcoma (24), Alveolar Rhabdomyosarcoma (3), Neuroectodermal (3), Sarcoma (2).	35.4 yrs (mean)	The study identified a profile for paediatric sarcoma patients who are most likely to have poor functional outcomes. Those with; lower limb extremity lesions (including pelvis and trunk), limb oedema, women with reduced ROM and weakness. As weakness and decreased ROM is associated with decreased mobility and aerobic capacity. Women cancer survivors may be particularly at risk from early development of cardiac disease. A battery of assessments would need to be used to identify at risk patients. AMPs scores were lower in the study group than control, Human activity profile (HAP) identified 50% had moderately or severely reduced activity. 8 participants identified cancer had a negative impact on vocations.	Self-report questionnaires used measure several factors in the same instrument. Small sample group.
2. Carty et al [23] AUSTRALIA	Retrospective subjective outcome study.	To apply disease specific measures to a group of intra-articular knee osteosarcoma pts and evaluate structural and treatment variables predictive of the functional outcome scores. Control	20 100% osteosarcoma.	No data	MSTS score was 25.0+/-3.0 (83%) with emotional acceptance and functional ability lowest ranked and pain and use of supports the highest ranked. ROM was slightly restricted in all patients. Mean knee extension strength was significantly reduced compared to the control group. Overall TESS scores; 86% with rising from kneeling (70%), kneeling 70%, participating in normal sporting activities 45%, walking upstairs 35%, walking up/down hill 35%,	Single centre study. Small sample size, a larger sample may have provided greater statistically significant results.

		group of healthy participants. Authors hypothesised that limb salvage patients would demonstrate reduced impairment and disability scores when compared to the normal population, and that there will be an association between impairment and disability scores.			getting out of bath 35%, performing heavy household tasks 30%, gardening 25% being reported as most difficult. Bivariate correlations showed a moderate positive relationship between MSTS score, knee extension strength and knee flexion ROM. MSTS moderately correlated with TESS scores p=0.02. An overall impairment outcome of 83% (mild impairment) was found. Results were consistent with amount of functional decline.	
3. Davidge et al [24] CANADA	Retrospective cohort study	To examine the relationship between pre-treatment outcome expectations and post-operative function and health related quality of life (HRQoL) in pts with extremity soft tissue sarcoma.	157 patients. 138 (88%) completed the expectations questionnaire pre-op 100% extremity soft tissue sarcoma.	16.1-87.0 years (mean = 56)	Pre-op expectations significantly predict functional outcome at 1 yr follow up. Baseline function was also a significant predictor of all 3 functional outcomes. No significant association between patients' expectations and HRQoL was found. Patients expecting a difficult recovery and patients with uncertain expectations had worse functional outcomes than patients anticipating an easy recovery. Expectations for length of recovery significantly predicted post op MSTS, TESS, RNL scores. Expectations for complications significantly predicted MSTS scores. Patient expectations for activity performance significantly predicted post op MSTS, TESS, RNL, EQ5D-VAS. Education, dispositional optimism, tumour location, AJCC stage, and baseline function/HRQoL were significant	Limited sample size, effecting the potential generalisability of results and Difficulty analysing results . The outcome questionnaires had not previously been validated with extremity soft tissue sarcoma patients. A range of Patient expectations and outcomes was not within the scope of this study which focused on function and HRQoL. The authors suggested future studies could investigate a wider range of patient expectations. Limited variables included in logistic regression analysis, resulting in other factors that might influence outcomes

					predictors of patient expectations.	being excluded.
4. Parks et al [31] UNITED STATES OF AMERICA	Cross sectional study.	Evaluated the late effects of pediatric sarcoma therapy by examining the ADL performance of long term survivors using a well-standardized ADL performance-based assessment. Study looked at survivors an average of 17 yrs after treatment	32 100% Ewings type sarcomas.	Mean 16.2 yrs Range 7.1 - 34.2	ADL motor ability was significantly lower for sarcoma survivors than for the age and gender matched comparison group ($p \geq 0.05$). Sarcoma survivors had significantly better ADL motor ability ($p \geq 0.05$) than the oldest comparison group (20 yrs older). Sarcoma survivors had significantly worse ADL process ability than the age matched group ($p \leq 0.05$). There was no difference in ADL process ability between the sarcoma survivors and the comparison groups that were 10 and 20yrs older. Study concluded that intensive multi-modal cancer therapy significantly influences pediatric sarcoma survivors ADL performance.	Small sample size and single centre study limit generalisability and significance of results. 2 control groups were older than the study group, although matched for gender. Significant follow up time so causative factors cannot be attributed solely to treatment.
5. Shin et al [28] UNITED STATES OF AMERICA	Cohort study.	To describe the experience of an acute in-patient rehabilitation unit of a national comprehensive cancer centre.	427 Sarcoma diagnosis 48 (11%)	No data	The centre discharged 75% of its patients directly home following in-patient rehabilitation. Highlighted challenges of rehabilitation engagement and participation due to extensive morbidity and mortality of patient group. Importance of appropriate rehabilitation goals, suggesting patients can set better goals if they understand their prognosis.	Single centre U.S study, although had a relatively broad geographical sample population, influencing generalisability of results to sarcoma population and potential for researcher bias. Patient experience evaluated using quantitative measures a qualitative aspect may have broadened patient experience.
6. Shehadeh et al [25] JORDAN	Retrospective cohort study	To establish a standardized postoperative rehabilitation protocol following limb salvage surgery (LSS) in patients with	59 (100%) primary bone sarcoma.	5-60 years (Mean = 24)	A standardised rehabilitation protocol resulted in improved functional outcomes. Rehab protocols implemented 4-8 month period of rehabilitation, and follow up at 24 months. MSTS-ISOLS mean score 87% (confidence interval 95% CI; 0.91-0.95). Scores highest in patients with distal femoral replacements 93% CI 0.91-0.95,	Small sample size and single centre study so results may not be generalisable and may be bias. Study had a short follow up time of 24 months (mean) and lack of control group.

		primary bone sarcoma			followed by proximal tibia 88%, midshaft tibia, femur, and humerus 87%, proximal femur 86%, proximal humerus and scapula 83%, pelvic resection 80%. Function plateaud at 4-8 months for all patients except pelvic resections who continued to improve up to 12 months post operatively.	
7. Hauken et al [22] NORWAY	Mixed method study	Does a goal orientated rehab program increase participation in young adult cancers survivors, and explore their experience of this process.	16 (11%) out of 31, completed analysis. Sarcoma – 1 (6%)	18-35 years	A goal orientated rehabilitation programme increases participation in young adults with cancer. Quantitative – Increased participation as measured by the Canadian Occupational Performance Measure (COPM). The change in performance and satisfaction based on the COPM from baseline and end of the programme (6 months) was clinically and statistically significant. Qualitative - In face to face interviews participants reported high levels of satisfaction with achievement of goals resulting in increased participation in personal, social and work life.	18-35yr olds any Ca diagnosis, only 1 patient with sarcoma representing 6% of the sample size. Overall small sample size may represent self-selection bias. Single centre study that did not include participants who dropped out of rehabilitation programme so results may not be generalisable so effect size may be limited. Women were also over-represented in the sample group.
8. Hudson et al [15] UNITED KINGDOM	Cross sectional study.	To review current rehab service available at specialist bone sarcoma units in England. The Quality Improvement Development and Innovation Scheme (QIDIS).	220 100% Primary malignant bone sarcoma.	≥18years	Study showed that current rehab provision is inconsistent and varies from centre to centre, creating an inequity of care. None of the centres currently provided a formal out-patient review at clinic only ad-hoc assessments when indicated. Inconsistent provision of rehab may affect patient's long term functional outcomes and QOL. The study concluded that 81.1% of upper limb patients felt their rehabilitation needs had been met this may be due to the majority of patients having surgery on their non-dominant limb. There was also a greater difference in TESS scores between upper limb major and minor surgery sub-groups,	Patient reported outcome measures were used there is no objective assessment. Results may have been skewed by patients with different surgical procedures e.g major/ minor upper limb surgery and the sample size may not have enabled classification of groups of patients based on procedure.

					but no significant difference in the lower limb group, authors suggested this may be due to lower limb patients having potentially less functional complexity in ADLs than the upper limb group. Minor surgery pts in both upper limb and lower limb group stated they would have liked more rehabilitation 45%. 73% of patients in lower limb group and 61.1% pts in upper limb group stated they would have benefited from an early or late rehab admission. Following analysis a post op model of rehabilitation was recommended.	
9. Fauske et al [32] NORWAY	Qualiitative study. Phenomenolo-gical and hermeneutic design.	To explore the experience of former cancer patients and the physical and psychosocial late effects 3-7 years following treatment for hip/ pelvic primary bone sarcoma.	10 100% bone sarcoma.	18-60 years	Patients reported different functional impairments that limit daily lives. Identifying 3 core spheres of impact "their daily life", their future opportunities, and their identity. Patients reported negative changes to their activity, increased dependence on others and exclusion from participation affecting their daily life, work, sports activities and social life. This may result in loss of identity.	A mixed method study may have gained a more complete picture of the consequences of cancer. The small sample size may be appropriate for qualitative research but also limits its generalisability. Participants were only interviewed on one occasion, several interviews over a period of time may have gained a more in depth picture of effects following treatment.
10. Michot et al [29] FRANCE	Case control, study.	Does enhanced recovery after surgery (ERAS) have a direct relationship to length of stay? Does ERAS in soft tissue sarcoma have an impact on post op outcome? Is it safe for pts regarding post op	734 patients. 257 patients were ER. 100% soft tissue sarcoma.	Mean in standard recovery group n =55, mean age in ER group n=58	The implementation of enhanced recovery (ER) protocols reduced length of stay without compromising post-op outcomes. Overall survival at 5 yrs was estimated at 80% (95% CI 77-83%). Table 3. Length of (LOS) for standard rehabilitation group 9, ER 3, P value ≤0.001. LOS dropped dramatically and this was maintained in a sub-group of patients with deep tumours as tumour characteristics may have influenced LOS. No negative post op outcomes	ER may have contributed to improved functional outcome scores however, radiotherapy was given more frequently given to SR patient post operatively and may have had a negative effect on function. Potential selection biases as patients were retrospectively selected in a time period. Patient characteristics may have changed over the

		morbidity and late functional outcome?		P=0.04	observed as morbidity was similar in both groups 42% standard and 36% ER. Readmission rates were unchanged. Functional outcome improved from 89% good/excellent to 94% ER.	period of time between the standard rehabilitation group and the enhanced recovery group. Tumour grade was also different in both groups which may have influenced surgical procedure and outcomes.
11. Gerrand and Furtado [8] UNITED KINGDOM.	Review	To explore the survivorship experience of patients treated with an extremity soft tissue sarcoma, the provision of rehabilitation services and discuss future direction.	Extremity soft tissue sarcoma.	N/A	Holistic, patient centred rehabilitation can positively influence survivorship. Delivering this within the financial constraints of the health care system can be difficult. Good rehabilitation should begin early in the treatment process involving discussion with patients and their families about outcomes, home and work environments, and roles. Delivering an individualised multidisciplinary plan can be challenging due to geographical location of patients attending specialist sarcoma centres. Rehabilitation can be delayed due to chemotherapy and radiotherapy. Few rehabilitation models have been identified for sarcoma patients. Post acutely focus on role development and return to work is beneficial. The International Classification of Functioning, Disability and Health (ICF) model is useful for understanding patients multidimensional needs. Participation restrictions have a significant impact of quality of life. Rehabilitation readmissions and wellness days after	Search strategy and methods were not described.

					treatment including physiotherapy, occupational therapy, pain management, benefits advice, psychotherapy and peer support may be beneficial. Evidence based developments in rehabilitation are required.	
12. Tobias and Gillis [14] UNITED STATES OF AMERICA	Review	Not specified	Extremity soft tissue sarcoma.	N/A	Early assessment of patients including home environments, care support, pre-existing independence, vocational status and return to work and financial concerns. Rehabilitation programs should maximize quality of life through recovering physical function, adaptation of the physical environment and maximising independence. Prehabilitation refers to the early intervention prior to surgery. An understanding of pre-treatment levels of function and tolerance for exercise and activities of daily living (ADLs) is required. Postsurgical management involves early rehabilitation depending on post op condition and recovery. Weight-bearing restrictions can affect bed mobility, transfers and ADLs. Functional outcomes focus on physical function including mobility and ADLs (TESS).	Written as an opinion paper, with review of relevant papers. Aims of review, search strategy, methodology not described.
13. Parsons et al [33] CANADA	Qualitative narratives.	To examine the relationship between the experience of osteosarcoma illness and experiences of vocation.	Bone sarcoma	16-35 years.	Data collected via in-depth interviews. Respondents were 1-6 yrs post op. Respondent's identified 3 types of work; illness work, identity work and vocational work. For most vocational interruption lasted 1 year or longer. Study can inform clinical practice by listening differently to patient's accounts and asking better questions. Clinicians should be aware	

					patients don't necessarily "pick up where they left off". Relationships to vocations were changed in wake of illness.	
14. Keegan et al [26] UNITED STATES OF AMERICA	Population based study.	To describe the unmet information and service needs of adolescents and young adult cancer survivors and identify sociodemographic and health related factors associated with unmet information and service needs.	Various cancer diagnoses, 25% sarcoma including Ewings sarcoma, osteosarcoma and rhabdo-myosarcoma.	15-39 years.	Service needs were identified by the authors as participation in a support group, seeing a pain management expert, professional advice regarding payment for healthcare and seeing a physical or occupational therapist for rehabilitation. The majority of cancer survivors in the study who needed services did not receive them. More than half of cancer survivors had unmet information needs. Subgroups pf adolescent and young adult (AYA) cancer survivors have the highest unmet information and service needs, particularly men, those of non-white ethnicity/ race, and with physical health and emotional problems. Unmarried, younger and lower education did not lead to findings of unmet need. Patients currently in treatment had fewer unmet information and service needs, this may be due to the focus on their current treatment or because they had frequent contact during their treatment with healthcare professionals.	Overall response rate was less than 50%. Unmet information needs may have been over estimated due to the survey design.
15. Schreiber et al [27] CANADA	Descriptive study.	To evaluate how functional disability impacts of health related quality of life (HRQOL) of patients with soft tissue sarcoma (STS) at 1 year post surgery.	Extremity soft tissue sarcoma.	Mean 55 years.	Participation restrictions significantly impacted HRQOL and participations in life roles has the greatest effects on HRQOL. Rehabilitation should focus on reintegration into normal life roles and reducing impairments. ADL restrictions are an important part of functional wellbeing but are frequently not measured.	

16. Saebye et al [7] DENMARK	Cross sectional study.	To identify tumour and patient related factors associated with reduced functional outcome and quality of life after limb sparing surgery in soft tissue sarcoma patients.	Soft tissue sarcoma	Median 61 years	Initial post-operative functional outcome is the best indicator of final functional outcome (at a year or more post-surgery). Gender, tumour location, radiotherapy and physiotherapy were associated with reduced outcomes in the TESS score. For the MSTS scores only physiotherapy was found to be significantly associated with reduced outcomes. Patients with lower extremity tumours had reduced functional outcomes based on the TESS than upper extremity tumours.	Surgeons only referred to physiotherapy if they found it necessary so those patients were most likely to have reduced function to start with. Potential bias of non-participants.
17. Davis [17] CANADA	Review	To review functional outcomes and predictors of patients treated for soft tissue sarcoma of the extremity, using the International classification of Impairment, disability and handicap model.	Soft tissue sarcoma	N/A	Outcomes for studies were classified using the International Classification of Impairment, Disability and Handicap (ICIDH). The authors found there was a lack of standardisation of outcome measures used. Impairment was the most frequently reported outcome measure e.g pain, reduced range of movement and muscle strength, edema and tissue fibrosis. Disability outcomes mainly related to physical health and handicap the most infrequently reported and used employment and vocational status. 50% of patients experience significant impairments following limb salvage surgery for soft tissue sarcoma. Less than 50% of patients reported difficulties with activities of daily living. Approximately 50% of patients were unable to return to previous vocations following surgery.	There was heterogeneity in patient population, treatment protocols and follow up. Predominantly studies did not use standardised, validated outcome measures. Most studies related to physical function.

					Psychosocial issues have not been reported. Higher levels of impairment than disability were found. There is a need for functional outcome measures that are valid and reliable to improve patient outcomes and inform clinical decisions.	