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Review

A scoping review of burn rehabilitation publications incorporating functional outcomes

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ABSTRACT

Objective: The objective for this manuscript is two-fold: determine the scope of clinical rehabilitation research involving burn-injured persons and assess whether research outcomes include function, return to needed, and desirable routines. Has this research addressed rehabilitation needs of the burn injured?

Methods: We performed a scoping review of literature (1990-2016) using the method of Arksey and O'Malley. Search terms included "rehabilitation", "function", "burn injury" and "work". Two independent reviewers identified articles that met criteria for abstract and full review. Variables of interest were counts of the number of intervention studies, studies performed in outpatient settings/inpatient settings, or both; count of the distribution of outcome measures that included impairment, function, participation, return to prior roles and percent of burns rehabilitation publications as a function of total rehabilitation articles published.

Results: Sixty-four articles were selected for review and 22 employed an intervention. Nine articles were intervention trials that used functional measures. Of the 22 intervention trials 3 (14%) were performed while subjects were inpatients, 9 (41%) while they were outpatients, and 10 (45%) while they were both. There were 67 articles that met inclusion for work-related studies. Fourteen were intervention trials, 9 utilized functional outcomes and 5 used impairment outcomes exclusively. Less than 1% of clinical rehabilitation research addresses burns injury and <1% of the randomized trials in rehabilitation relates to burn injury

Conclusions: There are few studies, few intervention trials and among these, very few that use function or return to community based activity as outcomes for people with burn injury.

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Contents

Introduction and background

The continuum of care for people who have suffered burn injuries includes acute, post-acute, and long term or survivorship care. This distribution of care over an extended time period is supported by the World Health Organization (WHO) model in that "health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" [1]. The WHO's overarching view of health is reinforced by 61 member countries and has not been amended since its inception, supporting the view that it remains generally accepted. The definition implies that health care includes treatments designed to prevent disability as well as restore and preserve function, a primary focus of the specialty of rehabilitation.

The field of rehabilitation research is a relatively new specialty hence, it is not surprising that there are fewer publications relative to other medical specialties. However, within the past few years, there has been significant growth in the overall number of publications in biomedical databases. In a 2016 search in PubMed, more than 1 million publications were produced in a single year [2]. Similarly, there has been significant growth in the number of publications retrieved when the MeSH term "Rehabilitation" is used. Within the rehabilitation literature, there has been an increase in published randomized controlled trials (RCTs), systematic reviews, and meta-analyses [3]. The growing number of rehabilitation publications indicates a continued interest and increased activity in rehabilitation research, an encouraging sign.

Burns rehabilitation has been a specialized area of rehabilitation whose contribution to the field has been the result of excellent efforts by clinicians and researchers. There are a small number of investigators performing burns research, many of whom are addressing surgical outcomes and morbidity and mortality. A few burns centers, some of which are supported by the Model Systems program, a national network of federally supported clinicians and researchers, have been instrumental in increasing the efforts to provide and evaluate rehabilitation outcomes for patients with burn injury. We have chosen to use a scoping review process to explore the extent of clinical rehabilitation research (CRR) publications that incorporate functional outcomes to learn more about what the field has been doing over the past 25 years.

The motivation for this undertaking is two-fold. The first is to determine the scope and kinds of rehabilitation research involving burn-injured persons that has been published. The second is to assess whether the outcomes of this research have had an impact on the practice of rehabilitation. In other words, is CRR providing information that advances the goals of rehabilitation, which include function, functional outcomes and return to needed and desirable routines; and hence considered useful or relevant to people with rehabilitation needs, care givers and the professional rehabilitation community. As mentioned above, function is a critical outcome for rehabilitation research, therefore we assume that relevant rehabilitation research should include outcomes that demonstrate improvement in function, social integration, participation in life activities such as school, work and avocations.

The literature supports the position that relevance has multiple domains and "relates to issues of external, social, and ecological validity" [4]. Several authors have written about the topic of relevance [5–7]. Generally speaking, research findings are likely to be used when the research results are seen as relevant to current concerns or needs [5]. Further, that the results are congruent with expectations and compatible with values and ideology [7]. Relevance relates to knowledge translation in that an individual's values and congruence with expectations are likely to influence acceptance and foster translation. This position has been elaborated by some who emphasize that the route to knowledge translation is a complex one that does not follow a linear process from research devised and executed by researchers, to results of these studies into practice. Rather, they suggest that researchers and stakeholders collaborate and create a series of action steps that lead to outcomes that engage multiple stakeholders including patients, caregivers, providers and payers (Bowen and Graham, 2013) [8].

The specific goals of this review included:

1. Establish the number of publications employing the search terms "rehabilitation" and "function" and "burns injury"
2. Determine the number of publications that were interventions
3. Identify the research design used for burn injury publications, such as randomized controlled studies
4. Determine the number and types of outcome measures used for burns injury
5. Ascertain the setting in which this research was conducted

To do this, we selected the scoping review process as best suited for our purpose. Several researchers (Arksey and

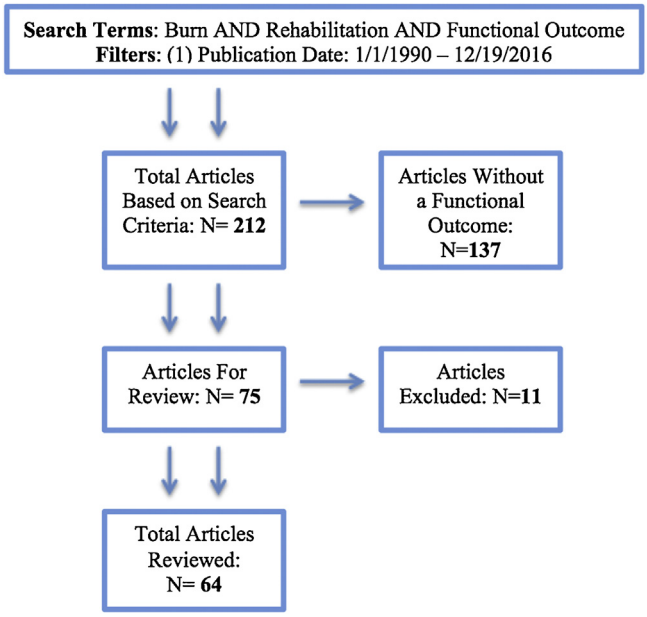

Fig. 1 – Scoping review process flow chart.

O'Malley, Levac et al., Daudt et al.) have proposed that scoping reviews serve two important purposes [9–11]. The first is that a scoping review seeks to present an overview of a potentially large and diverse body of literature pertaining to a broad topic. Secondly, they aim to provide a descriptive overview of the reviewed material without critically appraising individual studies or synthesizing evidence from multiple studies [9]. Arksey and O'Malley et al. proposed a 6-step process for conducting a scoping review: [1] identify the research question [2], identify relevant studies [3], study selection [4], chart the data [5], collate, summarize, and report the results, and [6] an optional consultation exercise [9]. Scoping reviews are widely used across many areas of investigation [12], however, recent publications have identified inconsistencies in the methodological standards for scoping reviews, which suggest improvements must be made to increase the usefulness and reliability of this review approach [13]. Consequently, there has been a significant effort to thoroughly approach the review with a more dependable and rigorous process. The Joanna Briggs Institute has developed a detailed manual of methodology for performing scoping reviews, while other additional options have been proposed [14]. Daudt et al. offers a straightforward and suitable method, suggesting that "scoping studies aim to map the literature on a particular topic or research area and provide an opportunity to identify key concepts; gaps in the research; and types and sources of evidence to inform practice, policymaking, and research" [11]. While the authors of this paper endorse the position of Daudt, we elected to follow the guidelines of Arksey and OMalley as their process has been frequently used and is generally accepted as reliable.

Methods

The protocol was prepared, reviewed, and revised by an advisory board consisting of members of the National Institutes of Disability, Independent Living and Rehabilitation Research Model Systems Burn Injury Program (RH, JS, PE) as well as an advisor with strong methodological background (AH). The search terms included "rehabilitation" and "function" and "burn injury". Two independent reviewers (HB, LG) reviewed the results of the original search and identified articles that met initial criteria for abstract review as well as articles that met criteria for full review. Results from this process are presented in Fig. 1. The list of articles selected is presented in Table 1 in the Appendix. The primary reasons for article elimination included non-human research and non-rehabilitation research.

Table 1 – Differences between PubMed publications between the years 1990 and 2016.

Publication Details	1990	2016
Number of PubMed publications	410,141	1254,449
Number of rehabilitation publications (% of total PubMed publications)	7136 (1.7%)	26,305 (2%)
Number of rehabilitation RCTs (% of total rehabilitation publications)	29 (<1%)	1334 (5%)
Number of Burns Rehabilitation (% of total rehabilitation publications)	66 (<1%)	226 (<1%)
Number of Burns RCTs (% of total burns rehabilitation publications)	1 (<1%)	10 (<1%)

We used standard terminology for this review:

a. Rehabilitation: that process whose aims are to improve, maintain or restore human function and to provide treatment or treatments designed to facilitate the process of recovery from injury, illness, or disease to as normal a condition as possible [15].
b. Impairment: any loss or abnormality of psychological, physiologic, or anatomic structure or function [16].
c. Function: a dynamic interaction between her or his health conditions, environmental factors, and personal factors. It is a composite of multiple domains when taken collectively represent human social, cognitive and social activities [17].
d. Participation/Integration: involvement of people in all areas of life, and the participation restrictions they experience (functioning of a person as a member of society) [17].

Variables of interest for the review included: a count of the number of studies that performed an intervention; a count of the studies performed in outpatient settings, inpatient settings, or a mixture of both; a count of the distribution of outcome measures that included impairment, function, participation, return to prior roles, and quality of life. Some instruments, used in the articles produced from this search, included ideas relevant to several domains and were scored as measuring any/all of them, (i.e. impairment, function, and participation measures). Examples might include measures of strength and range of motion (impairments) and mobility in a single instrument; or range of motion (impairment) and activities of daily living (function). The frequency with which the same outcome measure was used in the studies was tallied. In general, the sorting of the instrument domains followed the general outline of the ICF as described above. Instruments that measured more than one domain were scored for both.

In addition to the search described above, we performed a second literature search (sub-analysis) in order to establish if work related outcomes produced the same distribution of variables of interest as the general burn rehabilitation articles (Appendix Table 2). To complete this additional analysis the inclusion of the term "work" was added and the same process described above was followed:

1. rehabilitation AND function AND burn injury AND work (109 articles)
2. rehabilitation AND function AND burn injury AND return to work (28 articles)
3. rehabilitation AND function AND burn injury AND work outcomes (55 articles)
4. rehabilitation AND function AND burn injury AND vocational outcomes (2 articles)

We accessed the following URL: http://dan.corlan.net/medline-trend.html. to determine the publications by year. To determine publication trends from 1990–2016, we simply hit the "build trend" button without entering any search terms. To further examine publications trends by search terms and years, we used Mesh headings and the "results by year" bar graph in PubMed. Our first retrieval was "rehabilitation". We next added and "burn injury" and then "randomized controlled trials" for the final determination. We tallied the counts for each heading by year to provide the graphs.

Additional material is available in the Appendix that includes all articles reviewed for this paper. Publications that met criteria for inclusion (report a rehabilitation intervention and use at least one measure of function) are presented in **BOLD** font.

Results

The article review process presented in Fig. 1 produced a total of 64 articles that were selected for review. Among these reviewed articles, 22 used some type of intervention while 42 were determined to be non-interventional studies. The latter included descriptive, retrospective and follow-up studies, which may have begun as an intervention study.

The summary of the articles we included is presented in Table 1 in the Appendix. Variables selected for the analyses appear as column headings.

There were 9 articles that were both intervention trials and employed functional measures. (Table 1 in the Appendix). Among the 42 non-interventional studies, half [21] were classified as having impairment only outcomes while the other half [21] examined functional outcomes (Fig. 2). A similar analysis was performed for the 22 intervention trials. Nine employed functional outcome measures and 13 used an impairment scale exclusively.

Functional outcome measures were further classified into impairments, function/functional limitation, participation, societal integration, and quality of life. The frequency of these measures is summarized for all 64 selected articles in (Fig. 3). Some studies used a combination of domain measures; hence the total number of instruments exceeds the number of studies reported.

Of the 22 intervention trials, 3 (14%) were performed while subjects were exclusively inpatients, 9 (41%) while they were exclusively outpatients, and 10 (45%) while subjects were

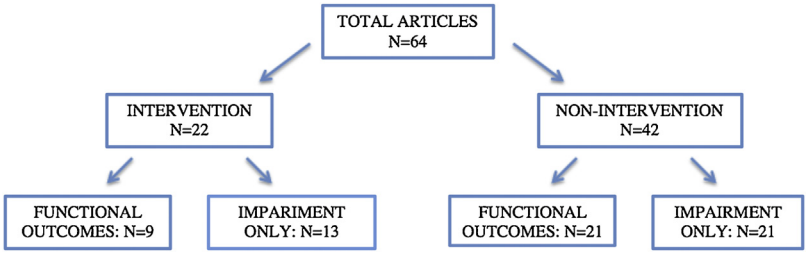

Fig. 2 – Reviewed article breakdown by intervention and classification status.

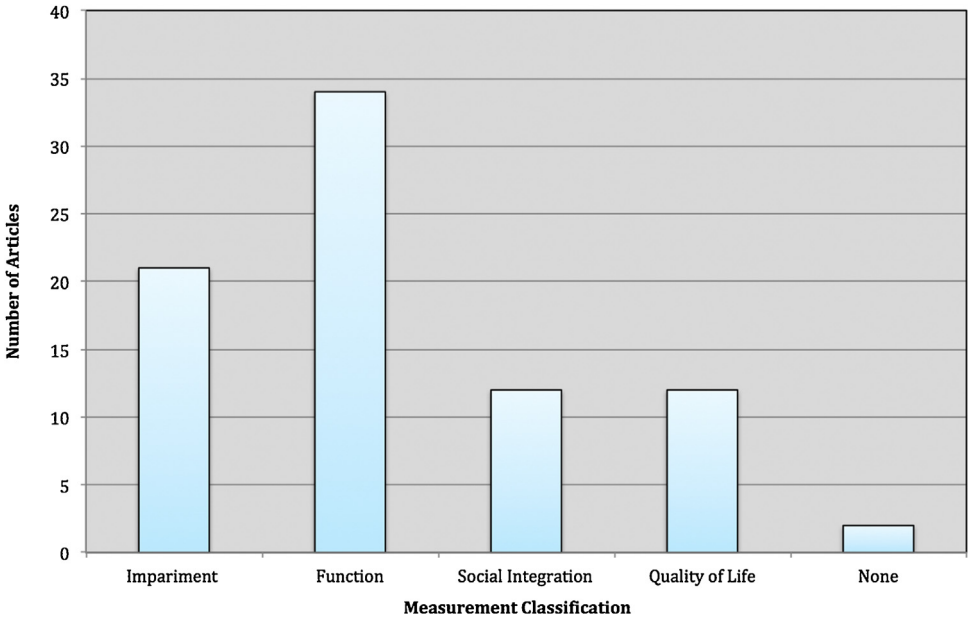

Fig. 3 – Reviewed burns articles (N=64) classified by measurement type.

inpatients and followed-up when discharged to outpatient status (Fig. 4).

The sub-analysis exploring the addition of the term "work" or "return to work" followed a selection process presented in (Fig. 5) (Table 2 in Appendix). There were 67 articles that met inclusion of which 14 were intervention trials and 53 were not (Fig. 5). The outcome measures of the intervention articles (n=14) pertaining to work are as follows: 9 utilized functional outcomes and 5 used impairment only outcomes (Fig. 6). We compared the instruments used in both the general scoping review for burns rehabilitation with the subset of work related outcomes. There is little overlap among outcome measures used for the general scoping review and those used for the sub-analysis assessing work related outcomes. Lastly, among the 14 intervention studies, 3 examined inpatients, 7 assessed outpatients, and 4 evaluated both.

Finally, we performed an analysis of the number of rehabilitation publications published in PubMed from 1990 through 2016 identifying the number of rehabilitation articles, the number of burns rehabilitation articles, the number of rehabilitation RCTs and the number of RCTs reported for people with burns (Table 1). Data are presented in graphic form for all aspects of the burns rehabilitation data, as well (Fig. 7).

Discussion

There has been an explosion in the number of PubMed scientific publications (410,000 in 1990 vs 1,250,000 in 2016) and an appreciable rise in rehabilitation publications over the past 25 years (7,100 in 1990 and 26,000 in 2016). This explosion has had an impact on the scientific community with the relative ease of "getting one's work published". A positive outcome of this growth is that the number of rehabilitation research publications seems to be increasing. Rehabilitation research

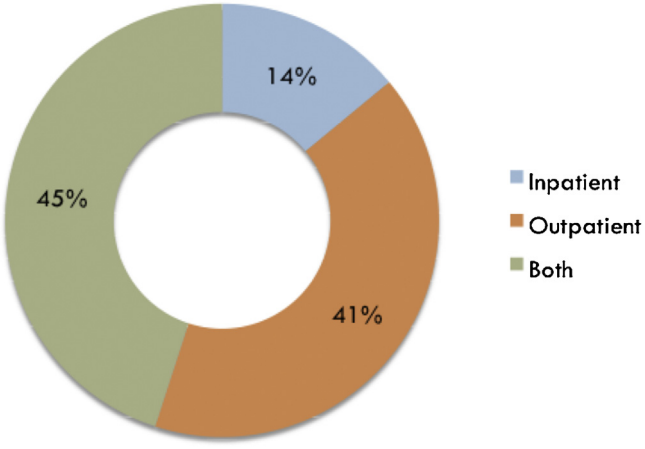

Fig. 4 – Frequency of research setting among intervention articles.

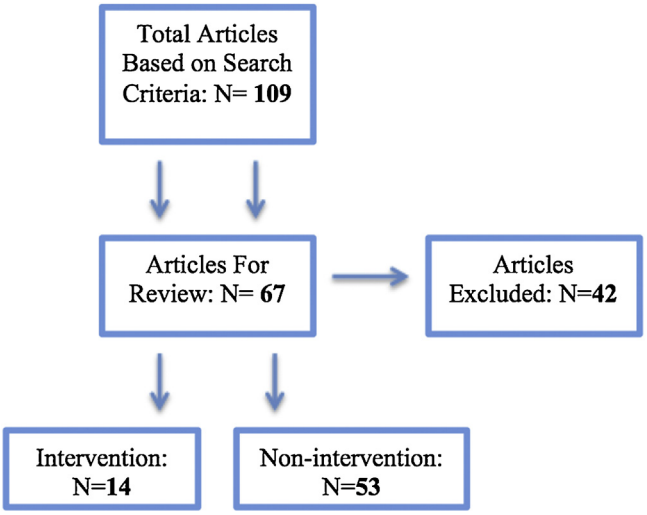

Fig. 5 – Selection process for burns sub-analysis.

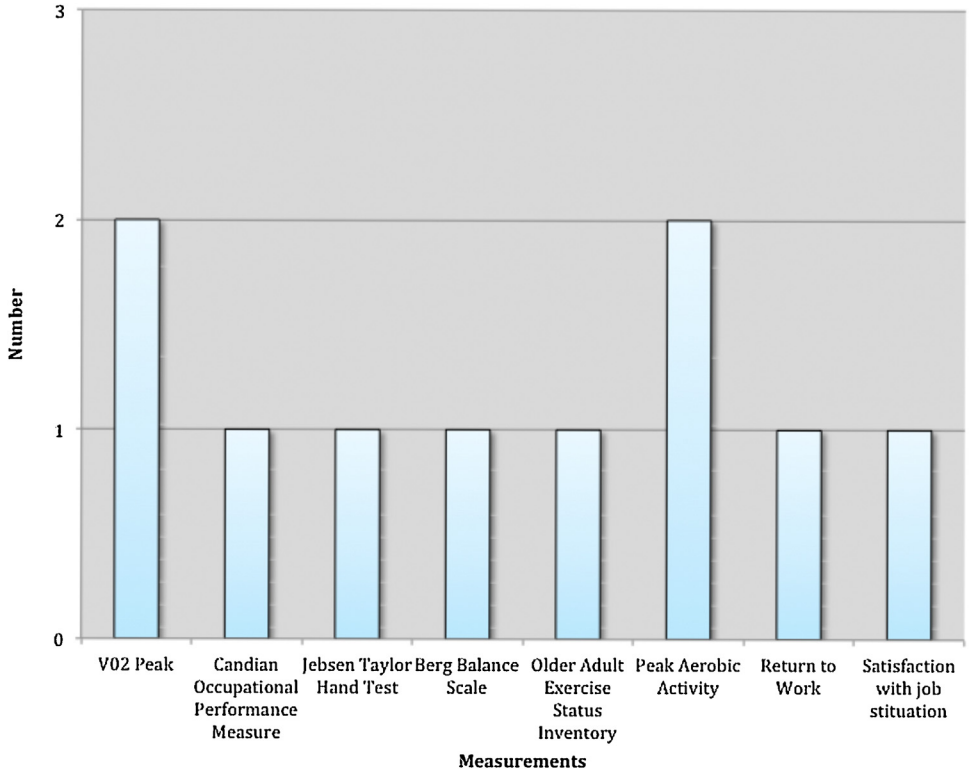

Fig. 6 – Frequency of measures among the functional group (N=9) of the burns sub-analysis.

publications, however, are at approximately 2% of total publications in PubMed in 2016, an increase from 1990 but still leaving significant room for growth. The contribution from burns clinical rehabilitation remains at <1% and no change from 1990. There is an increase in the number of rehabilitation RCTs to 5% in 2016, up from <1% in 1990. However, there has been no change in the number of published RCTs in the burns rehabilitation literature.

It is likely that the growth in the number of publications along with improvements in publishing technology that reduces turnaround time from submission to e-publication, have served to encourage researchers to publish. The relative ease of access to publications because of the Internet and the expansion of open access publishing have also contributed to greater demand and utilization of reading materials. This increased access to published materials, particularly open access journals, which enable one to read online for free, may have benefitted people with burn injuries and their families. Nonetheless, while this explosion has brought about some positive changes, it has also challenged clinicians and

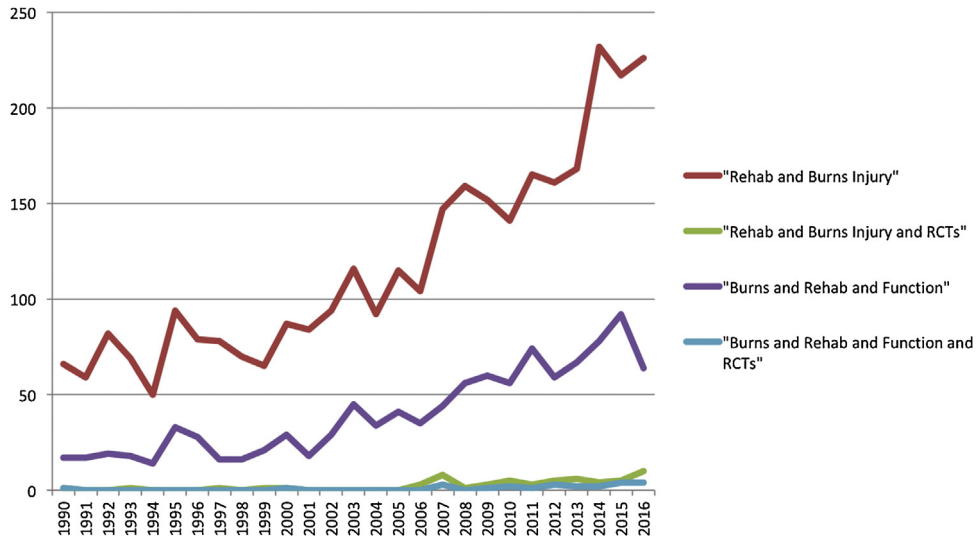

Fig. 7 – Trends in numbers of publications for articles meeting criteria for "rehab and burns injury" and "rehab and burns injury with randomized controlled trials" and "burns and rehab and function" and "burns and rehab and function and randomized controlled trials" in PubMed: 1990-2016.

patients alike. It has become increasingly difficult to keep up with the latest findings and recommendations, to navigate through the literature and find credible information and to identify relevant information [18]. Scoping reviews help summarize and organize the literature and can offer an approach that may facilitate the identification of factors that add relevance and meaning to the publications. In the present study, we selected a somewhat narrow focus which required that functional outcomes and information pertaining to participation, social integration, return to work and quality of life were included. In the authors' view this approach is the hallmark of rehabilitation and asks the kinds of questions many patients ask when they wish to understand the impact on their lives of their illness/disability and the effect of its treatment.

Therefore, we assumed that a desirable outcome for published CRR would include reports of functional change. That is, after a rehabilitation intervention, people would be more likely to do things that are needed and desirable in their lives. Furthermore, the acceptable way of assessing this was by the use of standardized instruments and well-accepted nomenclature for talking about rehabilitation outcomes. We then set out to assess whether studies identified as having a key word of "rehabilitation" and "function" actually used measures generally accepted as assessing functional outcome or/and measures of participation, integration into societal activities and quality of life.

This scoping review demonstrated that these types of functional measures are used in approximately 64% of the studies in which an intervention was employed and that the remainder used impairment measures exclusively. While the impairment measures are objective, provide important information to clinicians, and often help establish diagnoses, they are limited in terms of what they contribute to functional outcomes. It is our view, that impairment measures are not sufficient rehabilitation outcomes and when used exclusively, provide limited relevant information to patients and providers. Nonetheless, these findings may be a necessary condition for improved function and be linked to more relevant, functional outcomes. Another observation about these findings suggests that the search term "function" retrieves publications for which functional measures are not employed. The term function is used broadly, referring to all types of activities; and narrowly, referring to organ or system function. This is confusing to people searching for relevant information and could be improved if a more technical definition of human function were established.

We performed an additional sub-analysis and evaluated the same variables to determine whether the distribution of articles and outcome measures used were similar to measures used for general burn rehabilitation outcomes. The sub-analysis produced 9 interventional studies. Only 8 unique measures were identified, often a combination of objective and functional measures. It is interesting to note that the selected outcomes used for this analysis selected objective measures of performance that are often tied to specific work-related activities such as aerobic capacity, strength, dexterity and executive functioning. For example, the Jebsen–Taylor hand function measures dexterity and prehensile skills [19], an occupational performance measure (Canadian Occupational Performance Measure) [20] includes activities of daily living and daily routine assessment, and aerobic capacity. Several of these studies also included a measure of work satisfaction. In the authors' view, the selection of these combinations represents a point of view recognizing the need for a mix of measurement across multiple domains that assesses what the needs are of individuals whose successful outcomes require them to display certain behaviors and to perform complex activities and behaviors. In the authors' opinion, the combination of objective performance measures that address issues of function combined with patient reported outcomes (PROs) would provide reasonable functional measures for general rehabilitation outcomes. Using this approach

might provide a bridge between strictly impairment measures and function in this population.

This scoping review also identified that the field of burn injury rehabilitation uses many outcome measures. Some use only burns-specific measurements while others use generic outcomes, like the SF-36, which is a health status measure rather than a functional outcome measure. There is not a consensus about which ones to use. Not all conditions are best evaluated using the same generic functional measures. The psychometric properties, ceiling and floor effects, sensitivity to change etc are likely to make some more appropriate for certain conditions than others. The example of spinal cord injury(SCI) makes the point that the Functional Independence Measure is frequently used and generally accepted by the field of SCI professionals. However, Schneider [21] demonstrated its utility in the inpatient setting for patients with burn injury. Testing the validity of a generic instrument for a specific condition may be a result of how medical care is reimbursed in this country, and the fact that the FIM has been developed based on a huge database collected over many years from the Uniform Data System for Medical Rehabilitation and is now accepted as an instrument that can reliably assess independence and change over time among people receiving rehabilitation. Nonetheless, it is interesting that some of the standard measures for functional, multi-domain burn outcomes are not used more frequently. For example, the Burn Specific Health Scale and its abbreviated form [22] or the Young Adult Burn Outcomes Questionnaire [23] have not yet been universally used as an outcome measure.

We were unable to find studies using the newer item reduction technologies, such as PROMIS [24]. Many fields have applied the PROMIS technology to their research, which enables them to assess symptoms and function that cross diagnostic groups. It is the view of these authors that the field of burn injury rehabilitation would benefit from considering the use of a common set of functional evaluations. Further, the scope of the outcomes should include those that also address participation and societal integration/return to work, a very important goal for many burn victims. These measurements were rarely used. There are substantial opportunities for consensus development of a common outcomes measurement instrument bank for burns rehabilitation clinical research, evident by a recent publication arguing for developing a common data set in order to meet needs of patients with burn injury [25].

Another motivation for this scoping review was to determine the setting in which rehabilitation research is done. Hospital based studies are informative and enable ready access to patients and patient data. People receiving rehabilitation, however, are likely to be transitioning into community living and desire good functional outcomes and independence as treatment goals, when possible. Patients, caregivers, and professional providers all seek relevant information to help navigate the patient's transition to home, to provide a plan/program that continues to improve their function, and achievement of personal goals in their communities. We wished to assess how much research was performed in community outpatient settings and whether this research used different assessments. The data we report suggest that approximately 40% of the studies are performed in the outpatient setting. Almost 60% of these are studies that involve inpatients who are followed into the outpatient setting. The actual number [9] of studies designed to evaluate rehabilitation interventions for outpatients is quite rare. The paucity of studies evaluating people who have been discharged from hospital and are living in the community is a significant deficiency in burns rehabilitation research.

This scoping review has some significant limitations. One is that the search was conducted using only 2 standard databases. It also depends on the use of MeSH terms. While this provides standard nomenclature, authors use terms differently. Function occasionally refers to the working of organ systems rather than the whole person. The word rehabilitation is often applied broadly and may refer to interventions that only ameliorate symptoms or improve mood without having impact on function. Reviews of articles showed that 15% of articles were not relevant to rehabilitation and did not use instruments designed to evaluate outcomes relevant to rehabilitation. The search approach we selected was narrow and required that the terms "function" and "rehabilitation" be included in the aims of the study and were identifiable in the methods section. Further, that the outcomes selected for the study in fact were pertinent to function. If a specific study included these search terms, but did not have outcomes pertinent to function, it was excluded.

Another important decision was made about whether studies reporting symptom outcomes only should be accepted as meeting criteria for rehabilitation and function. The authors believe that there are many symptoms associated with burn injury and these may impact function. Examples include, psychological distress, fatigue, itching and pain. Treatment of these symptoms often, but not always improves function. If studies are aimed at symptom improvement without a concomitant assessment of function, they were not included in this scoping review, as we had no information about the impact on function.

Conclusion

Rehabilitation research in the field of burn injury represents a small fraction of rehabilitation research cited in the PubMed database, and has remained a very small fraction of CRR over 25 years. There were only 64 publications that met inclusion criteria for this review. The majority of studies retrieved were classified as non-intervention studies (n=42) and only 22 studies were intervention-based. The published literature in this field frequently includes impairment measures as the sole outcome measure, and fails to address function as an outcome of the study populations. Function is a defining feature of rehabilitation research and yet it is not universally used as an outcome in CRR. Further, this review suggests that there is no generally accepted functional outcome measure (or measures) used to best determine desirable outcomes. Only a small percentage of the studies were exclusively designed and executed in outpatient settings, which would likely provide much needed relevant information for our patients. Studies of work-related rehabilitation are an exception to this observation and the outcome measures for this activity are multi-domain, relevant and a mix of objective and self-reported

outcomes. This may serve as an approach that can be applied to evaluating outcomes of general burn rehabilitation, as well.

It is the belief of the authors that the findings reported in this study, a low number of intervention trials, limited use of functional outcome measures and limited number of studies that measure participation and return to community-based activity, might serve to encourage the more therapeutic intervention trials in both inpatient and outpatient settings.

Also important, is our belief that CRR routinely should use accepted functional outcome measures, possibly a uniform data set, and ones that evaluate return to work, school and other usual roles valued by individual patients. These are gaps identified in this scoping review and filling them is likely to improve the utility and relevance of the research to burn injury victims and their families.

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Conflicts of interest

The authors have no conflict of interest to disclose. All authors read and approved the final version of the manuscript.

Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at https://doi.org/10.1016/j.burns.2018.09.029.

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