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REVIEW ARTICLE

Telehealth for people with spinal cord injury: a narrative review

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Abstract

Study design Narrative review.

Objectives To find and discuss what has been published about the use of telehealth, on people with spinal cord injury (teleSCI).

Setting International.

Method Cochrane Library, Ovid Medline, EMBASE and CINAHL, from 1996 till June 2017 have been searched. Searches in PsycINFO, from 1996 till September 2017, were included afterwards. Extracted data include studies in English language, containing information about spinal cord injury and disorders, and telehealth. Literature reviews, systematic reviews, and studies containing other types of neurological disorders, were excluded. Studies were grouped based on how and to whom telehealth was offered.

Results Twenty nine studies were included in the review. They were categorized according to the way teleSCI was provided, and to what modality was used. Some studies utilized more than one modality. TeleSCI seems to be favorable concerning treatment and follow-up, as well as favorable socioeconomically and environmentally. The studies spanned across several aims and outcomes. There was also heterogeneity in number of participants, the differences in modalities, and in the level of evidence. Thus it was challenging to compare studies and make future recommendations.

Conclusions TeleSCI can be used for examination and guiding purposes. Further research is warranted to evaluate optimal utilization, methodology and efficacy.

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Introduction

One of the most significant changes in the practice of medicine has been the use of telemedicine [1]. Telemedicine can be defined as “the investigation, monitoring and

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management of patients and education of patients and staff, using systems which allow access to expert advice and patient information, no matter where the patient or relevant information is located [2]". Telemedicine was used as early as in the 1930s for telephone consultations for passengers on the Queen Mary [3]. Recently, the use of telemedicine has expanded rapidly with services available directly to patient for common concerns, such as upper respiratory and urinary tract infections [4] and through consultation from healthcare facilities for issues such as diabetic retinopathy [5], acute stroke [6] and intensive care unit patient management [7].

People with spinal cord injury (SCI) have difficulties with transportation and they represent a group that could benefit from using telemedicine services [8]. Moreover, there are few specialists who are qualified to care for persons with SCI/D and patients often reside far from their providers. At the International Spinal Cord Society (ISCoS) Annual Scientific Meeting in Vienna, Austria on 16 September 2016 [9], an international panel of leaders in telehealth services put on an instructional course regarding telemedicine and SCI/D, coining the term "tele-spinalcordinjury", or teleSCI. Subsequent to this forum, we determined a need to describe what has been published about this topic with the aim to find what is the status of the use of telehealth in the group of people with SCI. We chose to limit our search to only apply to this group, because of the profound mobility impairments associated with SCI as compared to other disabilities.

Method

Articles included in this narrative review [10, 11] are listed in Table 1.

Searches

Searches on the databases (The Cochrane Library, Ovid Medline, EMBASE, and CINAHL) were set to a time frame of 1996 to June 2017. These searches were carried out on October 15, 2016, November 16, 2016 and finally on June 6, 2017. PsycINFO was added with a search on September 5, 2017. Searches were created in collaboration with a Senior Librarian with expertise in medical science searches, working at the University Library of Oslo. Our search strategies included primary and secondary search terms in both medical subject headings (MeSH) and in title/abstract. Filter terms (year from 1996–current; English and Scandinavian language) were used to eliminate irrelevant articles (supplementary materials 1–2). We limited our search to the 1996–2017 period, because we wanted to include the use of primarily new telehealth technology. The English language

was chosen as filter term, supplemented by the Scandinavian languages, because three of the authors are familiar with these languages. No articles about the topic were found in any of the Scandinavian languages. The Ovid Medline strategy was adapted to the syntax and subject headings of the other databases (Supplementary materials 3).

Eligibility criteria

We included randomized controlled trials (RCTs), non-randomized studies, case series with more than five participants and interrupted time serial studies with more than ten participants, both genders and all ages. We excluded studies not in English or Scandinavian languages, literature reviews, systematic reviews, and studies containing a majority of individuals with other neurological disorders.

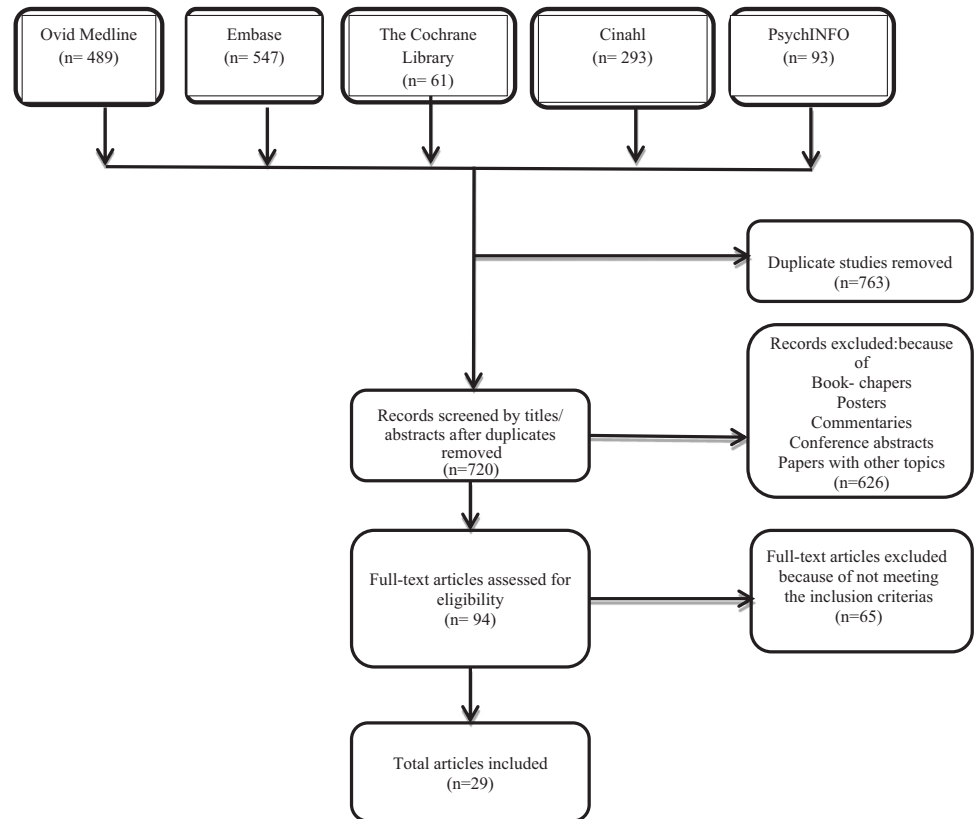
Categorization of articles

Only original research articles were included (Supplementary materials 4–7). Titles were reviewed first, followed by assessing relevant abstracts. Subsequently inclusion and exclusion criteria were utilized to determine which papers were selected for full reading and potential review. The results were divided into groups focusing on SCI and telehealth (teleSCI), with attention to how the teleSCI support was provided, leading to four different groups; voice only (telephone or mechanical voice), video plus voice (screen/videoconferencing), computer only (laptop/PC/tablets) and robotic voice or video (mechanical voice and/or animation). We then focused on to whom the telehealth service was given, and divided the results in five different groups, containing provider to provider (health care workers to health care workers or to other caregivers), direct to consumer (health care workers to patients), store and forward (transmission of information to health care receivers or users, not active live communication), web-based treatments (online education) and interactive home monitoring (e.g. with home based vital signs monitors) (Table 2). For purposes of our discussion, we use the term "direct to consumer" when care is included as one to one treatment to the home.

Outcome measures

TeleSCI plus standard care was compared to standard care alone, to evaluate the benefit of teleSCI. Standard treatment included general outpatient treatment and inpatient treatment. We included adverse effects in the grading, when presented in the studies. All effects are mentioned as presented in the studies along with a short explanation/definition for each, with the aim of documenting the overall effect of teleSCI. The degree various forms of teleSCI have been shown to benefit patients in psychosocial (mental health,

Fig. 1 Flowchart of the selection of articles



family, vocational counseling), medical (e.g., pressure sores, upper respiratory infections, spasticity), and functional (e.g., physical, occupational and recreational therapies) ways, are documented. Satisfaction, time and money saved, are reported when available (Table 1).

Selection of studies

The first author (II) conducted the initial search together with the librarian. The first author then chose the selection of studies for further investigation. The selection was double-checked by the last author (MAI). The librarian entered each selected article into a reference management database and duplicates were excluded (Fig. 1). Three groups of authors, two authors in each group (II and TR, NL and F B-S, MAr and RM), extracted information from the articles into a summary table (Table 1). Any disagreement in the groups was resolved by the last author (MAI). Each article that met the inclusion criteria is summarized in this table. Abstracted data included categories and modalities of the teleSCI used, diagnostic information, methodology, study design details, number of included/excluded individuals, number of individual responders, feasibility and outcome measures of the study (Table 1).

Data analysis

Following data extraction, study characteristics and variables were tabulated. Because of the small number of articles, the large heterogeneity in the study types, and because it was not possible to make a well-defined review question, both a formal meta-analysis and a structured review were deemed not eligible, and a narrative review was performed.

Results

A total of 1483 potentially relevant articles were identified (Supplementary materials 4–7). Duplicates ($n = 763$) were removed. Title and abstract screening identified 94 articles meeting the inclusion criteria for the abstract review, and the full text of the articles read. Twenty nine full text articles met the inclusion criteria for the review. Sixty five studies were excluded. A summary is provided in the flow diagram (Fig. 1). Detailed study results are presented in Table 1.

Based on the categories we found two studies considered provider to provider, 19 direct to consumer, one store and forward, six web-based treatments and three interactive home monitoring studies. Thirteen of the studies included the modality voice only, nine video plus voice, seven computer, and two robotic voice or video. In some of the

categories, teleSCI care was provided via multiple modalities (Table 2).

Provider to provider

Provider to provider treatment is used for collaboration between different hospital departments or between specialized health care and municipality. One retrospective study was classified as provider to provider [12]. In this study the authors looked at a convenience sample of veterans in the United States (US) with diagnosis of pressure ulcers (PUs), and then compared the costs of those veterans who had been treated with teleSCI, vs. those who had not been treated with teleSCI through the Veteran Affairs (VA) Decision Support System. Using this methodology, costs of providing specialty wound care to 76 SCI veterans by video plus voice teleconsultation vs. traditional care, in terms of inpatient admissions, bed days of care, outpatient visits, overall cost for outpatient care and overall cost for inpatient skin/ wound care were compared. The teleSCI group had more outpatient encounters (median 12 vs. 4, $p = 0.007$) and longer inpatient stays, compared to traditional care (81 vs. 19 days/admission). The median cost per outpatient encounter was higher (\$440 vs. \$141, $p < 0.0001$) in the teleSCI group. There were no significant differences in inpatient admission cost. This study retrospectively compared two groups—one treated with telemedicine, and we do not know the reasons why telemedicine was chosen for the individuals, or if all necessary information was loaded into the VA Decision Support System. We do not know the distance between the subjects and the facilities they received care in, the support systems or the degrees of PUs in the two groups, thus these results cannot be generalized.

Although not traditionally provider to provider, Careau [13], assessed the feasibility of video-conferencing for the inter-professional team managing people with SCI. Video conferencing was used to incorporate healthcare workers, community partners, patients and their caregivers as part of team meetings. Themes were assessed in 11 video conferencing meetings involving 47 healthcare workers, five community partners, eight patients and their five relatives. A typical videoconference involved 12 participants with average duration of 48 min. The authors noted a high rate of productivity (90.6%) along with very little time focused on resolving conflicts (5.5%) and discussion of unrelated topics (4.0%). “Significant changes of the client” were most often addressed (18.4%).

Direct to consumer

As a reference for whether teleSCI therapy is feasible, it is important to know what percentage of the SCI population actively engages in use of computer technology.

Hogan et al. [14] studied 290 US veterans. With a 38% response rate, findings revealed 64.8% of veterans used a PC, 62.9% used the Internet, and 26.2% used text messaging. In another article [34], the interrater reliability of administration of the SCI secondary condition scale by telephone, was tested in 40 individuals with SCI. Strong interrater reliability was noted with a paper version of the instrument. Another group [15] documented patient satisfaction in 29 persons who had received a teleconsultation after rehabilitation discharge. Thus, the use of direct to consumer teleSCI seems feasible. This is also what Houlihan et al. [16] found in their study, evaluating the impact of “My Care My Call” (MCMC)—a peer-led, telephone-based empowerment intervention. The authors concluded that “the MCMC peer-led, health self-management intervention achieved a positive impact on self-management to prevent secondary conditions in adults with SCI”.

A single-site, single-blinded RCT evaluating 168 individuals receiving usual care plus telephone counseling vs. usual care alone [17] evaluated self-reported health care utilization and medical complications, depression severity, current health state, subjective health and community participation in the US. The groups were similar at baseline, except that more control participants were married. There were no differences between the groups in a composite measure of health care utilization and medical complications, nor in psychosocial measures. Control participants reported fewer emergency/urgent care visits than treatment participants, thus one limitation of this study is that there may have been many participants who had little need for any intervention to address health or psychosocial outcomes. Perhaps results would be more robust if there had been identified participants with persistent problems requiring the intervention. Nevertheless, it appears that this direct to consumer intervention represents a promising approach to reducing health care utilization.

In another study [18], 137 participants with acute SCI from three sites in three different countries were randomized to teleSCI with video conference sessions, or to standard care. Treatment consisted of one teleSCI session every week for 2 months followed by nine teleSCI bimonthly sessions. Each session lasted 45 min and was one of two types; type one included a medical doctor and a nurse, and type two included a physiotherapist and/or an occupational therapist. Participants in the control group received the standard home-specialized, nursing-specialized, or unspecialized hospital care that they would normally have received after discharge. Outcomes included functional post-discharge status at 6 months, incidence of complications and participants’ satisfaction with the healthcare services. The authors reported the mean between-group difference in their analyses for all the outcomes. Based on the findings of functional independence measure (FIM) total

score (mean between group difference 4.31; 95% CI 1.27–7.35) and FIM motor score (mean between group difference 4.31; 95% CI 1.24–7.38) at one of the sites, the authors concluded that teleSCI direct to consumer may benefit patients discharged from a spinal cord unit, compared with standard care in terms of functional improvement. In a public health report [19], the effectiveness of teleSCI direct to consumer reduced the incidence of secondary conditions. 111 patients with SCI were randomized to video-conferencing using a compact equipment, telephone—using telephone line, or to standard care. Participants in the video and telephone groups received individualized educational sessions with a study nurse once a week for 5 weeks, then once every two weeks for 1 month in addition to standard care. Standard care provided participants a help line to call if and when they needed assistance prior to a 2-month post discharge visit. Interestingly, the authors did not report the mean between-group difference in outcomes in their analyses, but they concluded that telephone-or video-based interventions improve health-related outcomes for people with acute SCI living at home and that teleSCI may be cost-saving, using a direct to consumer strategy.

Emotional adjustment is an area that is amenable to treatment via telehealth. Dorstyn et al. [20] assessed the efficacy of telephone-based counseling vs. usual care to improve the emotional adjustment of 40 adults with SCI in Australia. All participants had recently been referred to inpatient psychology treatment, thus were considered to have baseline distress and in need of counseling post discharge. In the treatment group seven teleSCI sessions were delivered over a 12-week period, by a single psychologist. Pre-intervention and post-intervention data, plus a 3-month follow-up assessment, were compared with that of an SCI control group who received standard care which consisted of a single face-to-face consultation with a psychologist at 3 months post discharge. TeleSCI participants reported clinical improvements in depression, anxiety and aspects of SCI coping immediately post-intervention. Delivery related outcomes, including participation rate and cost analyses, were positive; however not statistically significant. Effects were also minimal at the 3-month follow-up; thus lasting benefits of teleSCI were not demonstrated. Results suggest that “continued psychological services for individuals reporting distress during their inpatient rehabilitation are important, and can be delivered direct to consumer cost-effectively, and efficiently by telephone [20]”.

Other studies document the efficacy of teleSCI with regards to physical therapies. One group [21] in the US performed a pre-post study of a convenience sample of 16 chronic SCI individuals with shoulder pain and manual impingement on exam. A 12-week exercise program was coupled with therapist video monitoring for technique and

exercise advancement. Outcomes including pain and function were measured at baseline, post intervention (12 weeks), and follow-up (>24 weeks) in a motion analysis laboratory. There was a significant main effect for pain and function between the three time points on the Wheelchair User’s Shoulder Pain Index, Disabilities of Arm, Shoulder and Hand Index, and Shoulder Rating Questionnaire. Isometric strength measurements of the serratus anterior and scapular retractors significantly increased after the exercise intervention. Muscle impulse produced by the lower trapezius during a fatigue task also improved. Limitations of this study are that there was no control group with individuals being treated at a facility. Moreover, it would have been interesting to see a cost and satisfaction analysis. Another group [22] developed and examined the feasibility, reliability and validity of tele-assessment of balance and leg strength in 22 persons with chronic SCI. Motor and sensory scores showed significant improvements at 6 months; however, there were no changes in balance scores. Overall, this technique had excellent inter-rater reliability for measuring leg force at maximum flexion and at maximum extension, and excellent intra-rater reliability for measuring leg force at maximum flexion, thus documenting the ability to effectively assess SCI persons with regards to physical changes via teleSCI. Effectiveness of the individual-level impact of a previously piloted exercise counseling intervention [23–25] was evaluated among 65 community dwelling adults with SCI in Canada to promote leisure time physical activity (LTPA). Fifty three patients participated in the evaluation of a 6-month, individualized telephone-counseling program, with focus on developing and strengthening clients’ social cognitions for engaging in self-managed LTPA. Efficacy evaluation showed that intentions for engaging in LTPA remained high throughout enrollment with a trend for more clients engaging in moderate-to-heavy-intensity LTPA at 6 months (52%) vs. baseline (35%) ($p = .09$). Conclusions were that telephone-based counseling is a promising strategy for promoting community-based LTPA.

Another group [26] performed a pilot study of an oral home telecare program training in the use of assistive devices, using a rechargeable powered toothbrush with brushing time display, a flosser and a universal holder so that the oral hygiene device could be fastened to their hand, and PC-based videoconferencing between each participant and an occupational therapist. Training consisted of five 15–30 min sessions over 3 months. Gingival health assessment occurred at baseline, six and 12 months. Statistically significant differences in gingival inflammation and improved dental hygiene behaviors were reported at six and 12 months compared to baseline evaluation. Lack of high-speed internet services reduced the participation rate, as did lack of computer literacy and software

incompatibilities. The authors commented on the inability to determine the extent of the contribution from the device vs. the telecare service.

Another utility of direct to patient teleSCI is for treatment and prevention of PUs. One group described a teleSCI system in Norway to provide specialist guided community-based follow-up for patients with PUs [8]. Home-based follow-up was provided for seven patients with PUs using video-teleconferencing technology with PC-based videoconferencing equipment, and an external web-based camera in the patient's home. The pilot program was cost effective at 15% of the cost associated with a regular outpatient clinic appointment and 3% of the cost of an inpatient admission. Patients and home nursing services reported favorable experiences with this direct to consumer and provider to provider system. Concerns included funding and coding for such services. Further research and extension of services was recommended. In another pilot, randomized trial of 30 individuals, evaluation of teleSCI with the use of telephone contact as a model of community-based care for people with SCI in Bangladesh [27], outcomes were measured in formation of PUs, mortality, complications, depression, participation and quality of life. One participant in each group died, two participants in the control group, and three participants in the intervention group had PUs at 2 years. Three participants were hospitalized for serious PUs, and six indicated that PUs had been a moderate or severe problem in the preceding 3 months. In a newly published RCT [28] including 120 participants with PUs, using a telephone-based intervention, the authors found that PUs healed significantly better in the intervention group vs. the control group. Despite these results, the authors said that their results weren't conclusive for recommendations. However, taken together, these two trials [27, 28] demonstrate the feasibility of using teleSCI to provide regular follow-up direct to consumer, after discharge, for people with SCI in low-income and middle-income countries.

Hill et al. [29] did a validation study of home telehealth for pressure ulcer assessments among patients with SCI. They compared the reliability and validity of assessments made via telephone and videoconferencing with a reference method, and found that "the agreement on the presence of a PU was excellent for both telephone and videoconferencing approaches (92% for telephone, 97% for videoconferencing). The diagnoses of the stage of PU made via telephone and videoconferencing showed substantial to almost perfect agreement with the inperson diagnoses (Spearman's rho of 0.76 and 0.83, respectively)". The authors write "There was a tendency for the measurements of wound volume to be somewhat larger in the telephone and videoconferencing modalities compared to those made in-person. Bland-Altman plots showed that videoconferencing gave substantially narrower 95% limits of agreement", and the

authors concluded that "the findings indicate that telephone can be a useful tool for identifying the presence of a PU, but videoconferencing is required to obtain an evaluation reasonably close to that of a home visit [29]".

In some of the studies in the "direct to consumer" group, the teleSCI participants received additional support/ therapy, and this might have resulted in improved outcomes for the teleSCI group. Further research should compare telehealth with equal amounts of traditional therapy or therapy similar to that offered via telehealth. Then it will be possible to compare whether teleSCI is a more cost-effective and efficient way to deliver post discharge health services.

Store and forward

Only one study [30] was found showing good efficacy of using stored images of PUs for teleSCI. With regards to deciding a treatment plan, the total percentage agreement between the tele-assessment decision and the live decision strategy was good, with an inter-rater reliability of 0.96 (0.93–0.98) and an agreement with paper version of 0.90 (0.83–0.95), indicating that tele-assessment of PUs in individuals with SCI using digital images may be a feasible option.

Web-based treatments

Seven studies [14, 30–33, 35, 38] referred to online monitoring (Table 2), four of them considered primarily web-based treatments. [31–33, 35]. In a pilot study [31] of a web-based self-management system for people with SCI utilizing intermittent catheterization (IC), 30 persons with SCI were enrolled, and 22 completed the entire program, which included three phone calls with a continence nurse and an online forum. The study also tested new self-efficacy-scales and self-management scales at the beginning and end of the study; however, they found no statistically significant improvement. According to the authors, this study "indicates that a web-based education program, following inpatient rehabilitation and also years after IC training, particularly when supported by phone, nursing consultation and online discussion, is likely to be well received by people who have a SCI [31]".

In another article [32], the pre-treatment and post-treatment effect of an online self-help program, Psyfit was evaluated. Seven out of 14 participants with SCI completed the modules, and the authors reported an increase in mental health, but a non-significant change in well-being. It was proposed that Psyfit may be a feasible program, but there were no significant results to support this in the article. The authors recommended further controlled studies, and they also recommended the use of teleSCI as a diagnostic tool.

Table 1 Articles included in the review

Category of study	Study number	First author/journal/year	Number of participants	Type of study	Aim of the study	Type of teleSCI	Outcome
Provider to provider	1	Young- Hughes S et al.; Rehab Nurs 2011 [12]	76	Descriptive retrospective correlation study	Compare the costs of providing speciality wound care to SCI/D veterans by teleconsultation and traditional care	Video + voice	No significant difference in inpatient costs for the two groups. The teleconsultation group had a significantly higher median cost per outpatient encounter
Provider to provider	2	Careau E et al.; J Interprof Care 2010 [13]	11-team meetings	Descriptive study of team meetings	Assess functioning of interdisciplinary team meetings via telehealth	Video + voice	Findings support benefits of videoconferences to coordinate patient care
Direct to consumer	3	Yuen J et al.; Spinal Cord 2015 [15]	29 with SCI/D 74 enrolled, 45 dropouts	Single group cross sectional	Evaluate patient satisfaction of the telemedicine consultation service follow-up	Voice only	Service of high quality and useful to the follow-up care found
Direct to consumer	4	Houlihan BV et al.; APMR 2017 [16]	84	Single-blinded randomized controlled trial (RCT)	Evaluate the impact of "My Care My Call" (MCMC) measured in health self-management global ratings of service/ resource use, health-related quality of life, quality of primary care	Robotic voice only	Positive impact on self-management to prevent secondary conditions in adults with SCI
Direct to consumer	5	Mackelprang JL et al.; Arch Phys Med Rehab 2016 [17]	168	Single-site, single-blind RCT	Reduce medical complications and health care utilization and improve psychosocial outcomes during the first year after SCI rehabilitation	Voice only	No significant differences between the two groups were observed
Direct to consumer	6	Dallolio L et al.; Arch Phys Med Rehab 2008 [18]	137 23 dropouts	Multi-site RCT	To compare the 6-month outcomes of telerehab intervention vs standard care for SCI	Video + voice	Positive impact of telehealth on patient satisfaction, no other significant changes
Direct to consumer	7	Phillips VL; et al., Public Health Reports, 116 Suppl 1, 94–102 [19]	111 randomized 47 with 12 month data	RCT	To study if telehealth can lower frequency of secondary conditions 12 months after SCI	Video vs. voice vs. standard	No difference at end of intervention, but telehealth group did better at 12 months
Direct to consumer	8	Dorstyn D et al.; Archives of Physical Medicine and Rehabilitation. 2012 [20]	40 adults	RCT	Does telephone counseling—feasibly improve emotional adjustment of adults with new SCI	Voice only	Clinical improvements in depression and anxiety and aspects of SCI coping immediately post-intervention. Not statistically significant
Direct to consumer	9	Van Straaten MG et al.; Arch Phys Med Rehabil 2014 [21]	16	Pre-post trial with outcomes measured at 3 time points	Effectiveness of a home telerehab program in reducing pain and increase function	Web-based treatment Video +voice	Pain reduced and function improved after intervention. Significant main effect for pain and function between the 3 time points, WUSPI DASH Index, and SRQ Isometric Significant increase of strength measurements of the serratus anterior and scapular retractors after the exercise intervention Muscle impulse produced by the lower trapezius during a fatigue task significantly improved

Table 1 (continued)

Category of study	Study number year	First author/journal/number of participants	Type of study	Aim of the study	Type of teleSCI	Outcome
Direct to consumer	10	Yozbatiran N, et al.; J Telemed Telecare 2010 [22]	Descriptive	Assess ability to measure balance and leg force with telehealth	Video + voice	Positive correlations between Δ in leg force and Δ ASIA scores. Δ in balance no significant correlations with Δ in ASIA scores
Direct to consumer	11	Arbour-Nicopoulos KP et al.; PMR 2014 [23]	Pilot intervention Descriptive	Assess the impact of telephone-based counseling intervention, using the first 2 components of the Reach, Effectiveness, Adoption, Implementation, and Maintenance framework	Voice only	Engaging in LTPA (leisure-time physical activity) remained high throughout enrollment, with a trend for more clients engaging in moderate-to-heavy-intensity LTPA at 6 months (52) vs. baseline (35%)
Direct to consumer	12	Arbour-Nicopoulos KP et al.; PM and R (internet) 2014 [24]	Pilot Descriptive	To assess intention to LTPA	Voice only	High intention to have LTPA; no significant increase to moderate-heavy LTPA
Direct to consumer	13	Latimer AE et al.; Rehabil Psychol 2006 [25]	RCT	Promote physical activity	Voice only	Engagement in physical activity after intervention. Sustained motivation and greater confidence
Direct to consumer	14	Yuen HK; Spinal Cord 2013 [26]	Single group—pre- and post-test design	Assess efficacy of oral home telecare program on gingival health	Video + voice	Statistically significant improvement from baseline at both 6 and 12 months
Direct to consumer	15	Irgens I et al.; Tidsskr Nor Lægeforen 2015 [8]	Pilot single group pre and post test	Assess efficacy of telemedicine for pressure sore healing	Video + voice	Intervention appeared successful and warranted further study
Direct to consumer	16	Hossain et al.; J Clin Rehabil 2016 [27]	Pilot RCT	Efficacy of a model of community-based care	Voice plus home visits	Feasibility proved Calls and home visits were delivered according to the protocol 87 and 100% of the time, respectively. Follow-up data were 99% complete
Direct to consumer	17	Arora M et al.; J Spinal Cord 2017 [28]	Multicenter, prospective, assessor-blinded, parallel randomized controlled trial	Determine the effectiveness of telephone-based-management of pressure ulcers in people with spinal cord injury in low-and middle-income countries	Voice only	Significant better healing in the intervention group. Two secondary outcomes (8 and 15) were significant
Direct to consumer	18	Hill ML et al.; J Telemedicine and telecare 2009 [29]	Observational	Reliability and validity of assessments and diagnosis made via home telehealth	Voice and video + voice only vs. gold-standard	Telephone can be a useful tool for identifying (phone 92 and videoconf. 97%), but videoconferencing is required to obtain an evaluation reasonably close to that of a home visit (phone 0.75 and videoconf. 0.83)
Direct to consumer	19	Elliott TR et al.; Behav Research Ther 2008 [36]	RCT	Examine the effectiveness of individualized problem-solving intervention delivered via videoconference for caregivers of people with SCI	Video + voice	Community-based, telehealth interventions may benefit family caregivers and their care recipients
Direct to consumer	20	Kowalczewski J et al.; Neurorehabil Neural Repair 2011 [37]	RCT crossover design	To compare 2 ET treatments delivered by in-home tele-therapy (IHT)	Video + voice	Scores improved more after ReJoyce ET (13.0 \pm 9.8%) than after conventional ET. RAHFT scores also improved more after ReJoyce ET than conventional ET

Table 1 (continued)

Category of study	Study number	First author/journal/year	Number of participants	Type of study	Aim of the study	Type of teleSCI	Outcome
Direct to consumer	21	Brody M et al.; Archives of Physical Medicine and Rehabilitation. 2015 [39]	7	Observational	Empowering, Information, Coaching SCI patients, Individual goal setting for individuals with SCI	Voice only	81% CALL COMPLETED 80% peer health coach calls were rated very good or excellent
Store and Forward	22	Halstead LS, et al.; Adv Skin Wound Care. 200 [30]	17	Pilot study	Compare teleassessment with live assessment of pressure ulcers	Web-based Computer +live assessment	Agreement between teleassessment and live assessment 89%
Web-based treatments	23	Wilde MH, et al.; J Wound Ostomy Continence Nurs. 2016 [31]	30	Single group pre and post test	Evaluate the feasibility of web-based intermittent catheter self-management intervention over 3 months	Web-based treatment	% catheterizing appropriate frequency increased from 71% to 77%. Other scores increased but not significantly
Web-based treatments	24	Verwer JH et al.; Spinal Cord 2016 [32]	14	Pilot Pre-test and post-test designs	To examine the feasibility of Psyfit in people with SCI	Web-based treatment	75% of the first and 39% of the second module were completed. Seven completed were included in the evaluation. Psyfit noted as useful and helpful for persons with SCI. Increase in mental health and non-significant Δ in well-being were seen at end of intervention, but weren't maintained
Web-based treatments	25	Migliorini C et al.; Spinal Cord 2016 [33]	48 persons 12 completed extended study	Prospective parallel waitlist RCT	Evaluate the feasibility and effectiveness of an Internet-based psychological intervention treating comorbid mood disorder in adults with SCI. Electronic Personal Administration of Cognitive Therapy (ePACT)	Web-based treatment	Significant improvement in mood in the intervention group lower depression, anxiety, and stress higher satisfaction with life control and group depression improvement (ES = 0.3)
Web-based treatments	26	Coulter E et al.; Spinal Cord 2017 [35]	24:16 intervention 8 usual care	Pilot RCT	Evaluate the compliance using a web-based physio exercise intervention	Web-based treatment	Feasible and acceptable. Good compliance Considered beneficial for health and well-being. Between-group differences, were insignificant
Interactive home-monitoring	27	Woo C et al.; Spinal Cord Medicine 2016 [34]	33	Pilot observational (Semi-structured qualitative survey)	Evaluate feasibility and benefit of the program	Computer only	DUSOI score decreased by nearly 20% HRQoL improved Efficacy proved-need to double check, not in abstract
Interactive home-monitoring	28	Hogan TR et al.; Am Academy of Phys Med Rehabil, 2016 [14]	290	Observational	Determine use of PC, Internet and text messaging amongst US vets with SCI	Web-based therapy	64.8% PC; 62.9% Internet, 26.2% text messaging. E-health Literacy score was 27.3
Interactive home-monitoring	29	Houlihan BV et al.; Arch PhysMed Rehabil 2016 [38]	7	Qualitative Pilot. Interviews	Determine feasibility, with focus on acceptability, demand, implementation and practicality	Web-based and peer-led telephone intervention	80% rated very good or excellent. Actual use: 88% completed. Use of resource list: 43% Use of workbook: 13% Implementation: 74% success rate in completing a call with a participant. Practicality: confidence toward meeting goals and feeling supported

Table 2 Characteristics of studies included in the review

Category of the study	Modalities of teleSCI			
	Voice only	Video plus voice	Data only	Robotic voice or video
Provider to provider		2		
Direct to consumer	11	7	1	
Store and Forward			1	
Web-based treatments	1		3	2
Interactive Home Monitoring	1		2	

Some of the studies utilized more than one modality

Interactive home monitoring

A descriptive report [34] discussed home monitoring with data messaging devices in 33 SCI males. The device included about 400 content items assessing a broad range of symptoms, educational needs, and self-management behavior recommendations. Improvement in clinical outcomes, care management practices, clinical flow processes and issues that needed to be addressed prior to broader protocol implementation were described in a subset of patients. Issues included accessibility and confidentiality concerns related to the program; however, overall the program was touted as a potentially excellent self-management, early education, home-based tool for newly injured SCI persons. Increased access to specialty care and early information received via the devices was hypothesized as potentially beneficial in allowing for earlier interventions and prevention of symptom worsening.

Discussion

In this review we have studied the status of to whom and how teleSCI has been offered for the last 20 years.

The actual number of articles included in the review was 29. Twelve of the studies were conducted as RCTs, nine were pilot studies, and the remainder were conducted as non-randomized, observational, or descriptive studies, mainly to see if teleSCI interventions were feasible (Table 1). Different aims and outcomes, and lack of information about selection criteria, different categories, and modalities, are weaknesses in the studies. As commented by Wilde et al. [31], “because of the small the number of participants, small changes could not reach significance, even if there was a trend”. These small sample sizes, makes it difficult to make any unified recommendations for the whole SCI population [31] or for further development.

Even though there are indications that teleSCI can be an effective means to communicate and collaborate, we are not yet able to conclusively document that teleSCI is an optimal means of interacting between health care professionals or between professionals and people with SCI/D.

Additionally, as this is an evolving field, the safety and security concerns needs further research.

Overall, studies highlight current issues in the performance of teleSCI. Yuen et al. [15], discuss the lack of high speed internet services reducing participation rate as did lack of computer literacy and incompatibility of participants’ computers with the videoconferencing program. The need for caregiver assistance to use an at-home-monitoring-program was emphasized by Woo et al. [34]. However, with successful provision of services there was high patient satisfaction [26] and services were found to be cost effective [8].

A confounding factor may be that a number of the studies [8, 17] didn’t evaluate the necessity of participating in the study. Thus, they may have included individuals with little need for interventions to address health or psychosocial outcomes, and findings may not be as robust as they would have been if all participants had clinical needs. Additionally, some studies could be placed in multiple categories (Tables 1, 2), making between study comparisons difficult. Other studies [21] compared various treatments performed via teleSCI, thus they were actually not assessing teleSCI vs. standard care. This makes it difficult to compare the use of teleSCI with other interventions, as well as to compare the potential of teleSCI to prevent development of complications. Therefore there are still unsolved questions about whether teleSCI is a good thing for people with SCI/D, and if it is good, for what acute and chronic problems is it better than in person care, for which is it inferior to in person care, and for which ones is it similar to face-to-face? We didn’t manage to find conclusive answers on financial implications or if there are adverse events to be aware of. We recommend to bear this in mind when future trials are planned.

Future recommendations for teleSCI

There are many companies developing telemedicine services to provide routine care to able-bodied individuals, and many benefits of telehealth are being recognized. Telehealth is environmental friendly with a lower impact in CO₂ emissions, and lower cost due to a decrease in travel.

Telehealth may also be ideal to use in times of disaster. It is convenient and saves time for the patient and high patient satisfaction rates have been found. Health care services like telepsychology [35] are relatively commonplace and telemedicine used in the group of patients suffering sequelae after stroke [6] is routinely used in rural hospitals. Moreover, insurance carriers are realizing the benefits of telehealth and it is being frequently reimbursed. Telemedicine is also being used more and more for emergency care and crisis management [7]. The lack of qualified providers, the high costs and burden of transportation for persons with SCI and their frequent common acute health problems, such as urinary tract infections, pressure sores and respiratory concerns, make teleSCI an ideal way to provide care. Similarly, long-term concerns, such as spasticity and pain management, are amenable to intermittent visits via teleSCI rather than repetitive visits to the clinic. Moreover, similar to the able-bodied population, the provision of psychotherapy, physical, occupational, speech and vocational services to persons with SCI/D, via teleSCI is appropriate. Finally, teleSCI to rural hospitals by an SCI specialist, could bring the possibility for more accurate diagnosis of acute SCI, so that optimal therapy could be provided.

As can be seen from this report, the predominant format that has been tested to date regarding teleSCI involves delivery of care directly from the provider to patient's homes. Store and forward is routinely used in radiology; however, limited research has been done on its benefits in the SCI population. Provider to provider would be an excellent platform for collaboration, and to develop services for persons with SCI. This is because the number of specialized professional caring for persons with SCI is limited; however, these services have not been tested. Moreover, provider to patient may also be performed in this type of setting when a provider at one facility provides care to a patient at a remote facility. Web-based treatments where the consumer receives therapy or training via a program accessed via the internet has begun to be developed for SCI, but such services are still in their infancy. Interactive home monitoring or the provision of automated monitoring services to patients in their homes, are beginning to be developed.

Developing a teleSCI program requires resolution of defined key issues to ensure services are safely provided. Use of a secure communication platform is necessary to ensure appropriate confidentiality of patient information. Appropriate consent must be provided, and safe and secure downloading of the necessary software must be given priority. State and country licensure regulations for services provided must be considered as must privilege concerns and accreditation processes. As regulations for these services are varied, it is important for the provider to be knowledgeable about the exact locations they are practicing.

One major barrier for the provision of teleSCI services is the issue of insurance. Local and national issues need to be taken into account. Finally, the issue of reimbursement must be investigated. Although some national and private insurance companies are providing reimbursement for telehealth, the rules are constantly changing and each system and provider will need to determine the cost/benefit of the provision of teleSCI services. Additionally, equipment needs and whether peripheral devices are necessary to view details of PUs must be considered.

TeleSCI has the possibilities to support both patients and providers with face-to-face communication at a distance. It seems to be a useful, safe and cost-effective tool applied in different modalities, by different members of the multi- and interdisciplinary team, with possibilities for better user participation from the patients. Future work will require standards of care for teleSCI services and research that addresses user-participation, safety, efficacy, cost-benefit and quality of life. A standardized dataset may also be appropriate to describe telehealth interventions for persons with SCI. This should allow future research to be conducted in a fashion that will allow comparison of patient populations, accessibility to technology, treatment interventions and efficacy.

Conclusion

The use of telemedicine has expanded rapidly [1], and both inpatient and outpatient services are available directly both to patient and caregivers for common concerns. These services seem to be socioeconomically and environmentally favorable. Yet, we do not have enough evidence about optimal methods for utilization, methodology and efficacy of teleSCI. We need continued research to evaluate, so that further development and expansion will be for the best of both caretakers and caregivers.

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Author contributions All the authors contributed in designing the review protocol. The first author (II) conducted the initial search together with the librarian, and the last author (MAI) double-checked the selection. II and TR, NL and FB-S, MAr and RM, extracted the data. Any disagreement was resolved by MAI. II and MAI prepared the figures and wrote the manuscript. All authors edited and critical reviewed the manuscript, and approved the final version of the manuscript.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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