

Review

Follow-up care for persons with spinal cord injury living in the community: a systematic review of interventions and their evaluation

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Study design: Systematic review.

Objectives: (1) To describe and compare follow-up care programmes, performed by rehabilitation centres, for persons with spinal cord injury (SCI) and (2) to describe the effects of these programmes regarding the occurrence of secondary impairments, well-being, the quality and costs of care.

Methods: A systematic literature search was conducted in MEDLINE (1972–2003) and CINAHL (1982–2003). Publications were selected about medical and/or nursing follow-up care to SCI patients living in the community performed by or with rehabilitation facilities for SCI patients. The aim of the follow-up care should be a decrease of secondary impairments, an improvement of well-being, an improvement of the quality and/or a decrease of the costs of care.

Results: The search resulted in 24 papers. The descriptions of the programmes in these papers were sometimes rather scattered, vague or brief. The most important methods were telemedicine (six programmes; of which five were performed in the same rehabilitation centre), outpatient consulting hours (six programmes), home visits (three programmes), and case management (one programme). Eight other programmes combined several methods (ie outpatient consulting hours, home visits, peer teaching and support, outings, ongoing support, therapy from several care disciplines, SCI education, providing SCI expertise and support to community health-care providers, coordination of care with community nursing agencies). In all, 16 programmes have been evaluated to some degree. In general the quality of the studies was low. Most evaluations were pre-experimental in design. Only three were quasi-experimental, and two programmes were experimental in design. Although several studies claimed positive effects, it was not possible to draw conclusions on the effect of follow-up care on the occurrence of secondary impairments, well-being, the quality and costs of care.

Conclusion: There is a need for the development, the publication and the well-designed evaluation of follow-up care programmes for persons with SCI.

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Introduction

Since persons with spinal cord injury (SCI) are confronted with all kinds of short- and long-term problems in functioning after discharge from initial rehabilitation, the need for continuing care for persons with SCI living in the community has been emphasised in several reports.^{1–8}

Until recently follow-up care provided by the Dutch rehabilitation centres has consisted of periodical outpatient visits to a physiatrist. During these visits a comprehensive assessment of total functioning is performed and, if necessary, interventions or other support is given. After discharge from clinical rehabilitation, daily medical and nursing care for persons with SCI is usually given by primary care professionals. As a result of the low prevalence of persons with SCI, primary health-care professionals only sporadically have persons with SCI in their practice. Consequently, they do not

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often have much opportunity to gain sufficient knowledge and experience about the specific care these patients need. As a result of this and the high prevalence of health problems, rehabilitation teams want to extend their role in follow-up care to persons with SCI living in the community.

In order to be able to learn from other initiatives regarding follow-up care, this systematic review was initiated. At present there is no systematic overview of the content follow-up care programmes and the effects on the prevalence of health problems.

The purpose of this paper is to provide an overview of published follow-up care programmes provided by rehabilitation centres to persons with SCI after their in-patient and outpatient rehabilitation. This study is focused on medical and nursing follow-up care, since most problems SCI patients experience are within the scope of the medical and nursing profession. The second objective is to describe the effects of these published follow-up care programmes on the occurrence of secondary impairments, well-being, the quality and costs of care.

Methods

Search strategy

Publications were selected from the MEDLINE (1972–2003) and CINAHL (1982–2003) databases. In all search strategies we combined several terms for spinal cord injuries (ie tetraplegia, paraplegia, spinal cord injuries) with a broad range of keywords related to follow-up care (ie follow-up care, long-term care, aftercare, continuity-of-patient care, patient discharge, outpatient care, ambulatory-care-facilities, primary-health care, home care, home rehabilitation, community care, disease management, shared care). The search strategy is described in Figure 1. The definition of a keyword given in the thesaurus list of the databases was used to determine whether a keyword was appropriate to use in the search strategy. Only publications written in Dutch, English or German were taken into consideration.

Selection procedure

A publication was selected if it described medical and/or nursing follow-up care to persons with SCI living in the community after their in-patient- and outpatient rehabilitation. The aim of the follow-up care should be a decrease of secondary impairments, an improvement of well-being, an improvement of the quality and/or a decrease of the costs of care. Furthermore, it should describe follow-up care performed by or in cooperation with rehabilitation facilities for SCI patients.

The first phase of the selection was performed by three investigators (LW, MP and JB) by reading the titles and, if available, the abstracts of all the initially identified publications. All publications selected by at least two of the three investigators were obtained and studied by the first investigator (JB) in order to

- #1 spinal-cord-injuries or quadriplegia- or paraplegia-
- #2 #1 and follow-up care or telephone follow-up or follow-up call or follow-up visit or follow-up intervention or follow-up service or follow-up programme or follow-up system
- #3 #1 and long-term-care
- #4 #1 and aftercare*
- #5 #1 and continuity-of-patient-care
- #6 #1 and patient-discharge
- #7 #1 and outpatient-clinics-hospital or ambulatory-care-facilities
- #8 #1 and home-care-agencies or home-care-services-hospital-based or home-care-services
- #9 #1 and primary-health-care or community-health-services
- #10 #1 and disease management
- #11 #1 and shared care
- #12 (#2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11)

Figure 1 Search strategy

determine whether the inclusion criteria mentioned indeed were applicable. In case of doubt on selection of a publication, the other investigators were consulted.

Assessment of selected follow-up care interventions

The follow-up care programmes were systematically described with respect to the aims, target population, method, responsible care disciplines, and content of the follow-up care. If there was a control/comparison group, the content of the treatment the persons in this group received was also described.

Follow-up care programmes that had been evaluated were described with respect to design, number of patients, outcome measures, and results. The studies were categorised as experimental, quasi-experimental or pre-experimental, according to the classification as described by Polit and Hungler.⁹ In this classification an experiment is defined as a study in which the investigator controls (manipulates) the independent variable and randomly assigns subjects to different conditions. Quasi-experiments involve manipulation but lack a comparison group or randomisation. In quasi-experiments efforts are made to introduce controls to compensate in part for the absence of one or both of these important characteristics. Pre-experiments do not include controls to compensate for the absence of either randomisation or a control group.

Results

Results of the search strategy

The search for publications resulted in almost 800 titles of which 99 were selected by at least two of the three researchers as being possibly relevant. The types of these 99 publications varied. Only a minority had a scientific format, including an abstract, introduction, methods, results, discussion, and conclusion section. Also some

letters to an editor, a job description, and a research abstract were included. Sometimes it was hard to decide whether or not to include a publication, because, for example, the information about the follow-up care was too brief. Finally, 24 of the 99 initially selected publications were included in this review.

The reasons for not including the remaining 75 publications varied. A total of 17 publications focused on the care during rehabilitation and discharge-preparation, 10 publications focused on the importance of follow-up care, but did not describe a programme, eight publications described or evaluated care provided by primary care professionals only, two described in-patient care programmes for patients readmitted due to pressure sores, two publications reported health problems after discharge, and the remaining 35 publications were excluded for all kinds of reasons (eg publications focusing on the importance of good education materials, a well-organised continuum of care, health problems after discharge, case descriptions not dealing with follow-up care provided by the rehabilitation centre).

Intervention characteristics

Table 1 displays the aims, methods used, care disciplines responsible, and content of the follow-up care programmes identified.

Principle methods of the follow-up care programmes Five methods of follow-up care could be identified from the descriptions in the selected articles:

- (a) Telemedicine, the use of telecommunications technology that either delivers or supports the delivery of health services and education via long distance.^{10–15} Five of these six projects were performed by the same rehabilitation centre, that is, Shepherd Centre, Atlanta, USA. Since both the content and to some extent the aims were different for each follow-up care programme, all these projects were included in this review.
- (b) Outpatient consulting hours providing physicals, reviews of daily functioning and support in case of health problems.^{16–21}
- (c) Home visits.^{22–24}
- (d) Case management, involving the coordination of care within, between, and beyond the acute and rehabilitation programmes, extending care and coordination to the community and managing the reemerging needs of the population over time.²⁵
- (e) Miscellaneous types of follow-up care consisting of several of the following methods: outpatient consulting hours, home visits, peer teaching and support, outings, ongoing support, therapy from several care disciplines, SCI education, providing SCI expertise and support to community health-care providers, coordination of care with community nursing agencies.^{26–33}

Aims of follow-up care programmes Prevention and/or treatment of secondary impairments was the most frequently mentioned aim of the follow-up care programmes. Two-thirds of the follow-up care programmes included this in their aims.^{10–14,16–18,22,24–30} Six follow-up care programmes solely aimed at the prevention and/or treatment of a specified secondary impairment: pressure sores,^{10–13,17} and urinary tract infections.¹⁶ Beside this, several of these programmes also had a broader aim like the promotion of well-being and community reintegration.^{12,18,22,25,26,28–30}

In several publications^{13,18–22,28,29,32} the aim of the follow-up care was not stated explicitly, although in most cases an aim could be derived from the text.

Target population of follow-up care programmes The target population in all follow-up care programmes was persons with SCI recently discharged from rehabilitation and living in the community. Some care programmes also involved in-patients.^{17,25,31,33} The follow-up care programme described by Beck²⁶ was designed for persons with tetraplegia and their long-term health-care providers. Several care programmes regarded persons with SCI and their partners or families.^{19,21–25,27,32,33}

Responsible care disciplines Almost half of the follow-up care programmes were performed by nurses.^{10–14,16,22,24–26,35} The remaining programmes were performed by several care disciplines. In the follow-up programme described by Pollack,³¹ the participants had coresponsibility in the performance. The follow-up care programmes described by Dover,¹⁷ Lapierre,²⁰ and Dinsdale²⁸ were performed in collaboration with primary health-care providers. Several follow-up care programmes^{15,21,23–26,28,30} paid attention to the coordination of care with community care agencies/providers, for example, by providing SCI expertise, support and communication of information regarding assessments and treatment plans.

Content of the follow-up care programmes The degree in which the content of the follow-up care programmes were described was very diverse. The content of patient-caregiver contacts or education were for instance sometimes elaborated, and sometimes not. Sometimes it was hard to distinguish the difference between the follow-up programme and usual care. Sometimes the description of the content of follow-up care described rather scattered, vague, and brief.

Except for the follow-up care described by Steinberg,³² the programmes did not include home therapy or home health aid, for simple nursing procedures such as baths, enemas, etc. Most follow-up care programmes had a supportive, consultative and educative character.

Table 1 Follow-up care characteristics

<i>Author</i>	<i>Aim</i>	<i>Principle method</i>	<i>Care disciplines responsible</i>	<i>Content</i>
Mathewson ¹⁰	Long-distance delivery of medical education and services to patients with pressure ulcers	Telemedicine	An ET nurse (abbreviation not explained)	Distant care using a videophone (audio and still images) Structure: weekly contact for 5 weeks and then every other week
Mathewson ¹¹	To prevent pressure ulcers	Telemedicine	A wound, ostomy and continence nurse	Two interventions: (1) Telerehabilitation: distant care using a videophone (audio and still images); Structure: weekly contact for 5 weeks and then every other week (2) Contingency management: a procedure whereby the patient receives monetary compensation upon keeping his skin free from pressure sores Weekly videophone contacts (audio and still images)
Phillips ¹²	To prevent pressure ulcers and to assist in community reintegration	Telemedicine	A nurse	Weekly videophone contacts (audio and still images)
Phillips ¹³	Not described directly Indirectly: to prevent pressure sores and hospitalisations due to pressure sores, to promote the most effective care of sores that develop	Telemedicine	Video group and telephone group: a nurse standard care group: not described	Two interventions: (1) Video intervention: videophone (audio and still images) and telephone counselling sessions providing support related to pressure sores, problems related to wheelchairs, mattresses, and mobility; Structure: weekly videophone contacts for the first 6–8 weeks following discharge, followed by weekly telephone contacts for 4–6 weeks (2) Telephone intervention: telephone counselling providing skin checkups and support related to diet, bowel problems or other problems; Structure: weekly contacts for approximately 10 weeks after discharge The comparison group received standard care: information and counselling for patients who call the help line of the rehab centre
Phillips ¹⁴	To reduce the incidence of secondary conditions	Telemedicine	Video group and telephone group: a nurse standard care group: not described	Two interventions: (1,2) Video and telephone intervention: individual educational sessions regarding skin care, nutrition, bowel and bladder routines, psychosocial issues, and equipment needs Referrals to a mental health counsellor or other professionals if necessary The video group also saw real-time images of the nurse (audio and still images) Structure: weekly contacts for 5 weeks, then once every 2 weeks for 1 month The control group received standard care: requires patients to call the help line of the rehab centre
Weinel ¹⁵	To reduce reliance on in-patient care and redirect resources to community settings	Telemedicine	Several care disciplines	A hub-and-spokes model is used to link a major spinal cord injury/disease (SCI/D) centre to nonspecialty outpatient clinics

Table 1 Continued

<i>Author</i>	<i>Aim</i>	<i>Principle method</i>	<i>Care disciplines responsible</i>	<i>Content</i>
Barber ¹⁶	To reduce urinary tract infections in patients identified as at risk	Outpatient consulting hours	A nurse	<p>Veterans present themselves to the satellite outpatient clinic nearest their homes. After that a teleconsultation visit is arranged with the appropriate interdisciplinary team member at the SCI/D centre. Each outpatient clinic has a 2-way interactive video module and a personal telemedicine module containing a speakerphone, blood pressure and pulse meter, a telephonic stethoscope, and a handheld digital camera.</p> <p>Review of patient's urologic history, medical interventions if necessary, counselling (one session; 15–30 min) by the nurse with respect to proper clean intermittent catheterisation, hygiene, and other aspects of bladder management. If the patient had multiple urinary tract infections during the following 6 months, continuous low-dose antibiotics were initiated. Counselling was repeated during subsequent clinical visits. All activities are described in a care path.</p>
Dover ¹⁶	To assess, advise and educate with regard to pressure sore prevention To assess each patient's susceptibility to pressure sores To link with the community liaison nurse	Outpatient consulting hours	A nurse and an occupational therapy technician from the rehabilitation centre, and a community liaison nurse	<p>Visits to a clinic (both in-patient and outpatient), in which patients are taught to take responsibility for their own well-being, an education programme, and home visits by a community liaison nurse after discharge.</p> <p>The comparison group received their in-patient rehabilitation in another rehabilitation centre and were attending the pressure clinic as outpatients for the first time.</p>
Dunn ¹⁸	Not described directly Indirectly: wellness, health promotion, and illness prevention. To prevent and reduce the number and severity of secondary conditions	Outpatient consulting hours	Several care disciplines	<p>A comprehensive, interdisciplinary primary health-care follow-up (not being described in more detail). The comparison group did not receive health-care follow-up.</p>
Ferguson ¹⁹	Not described	Outpatient consulting hours	Several care disciplines	<p>Annual physicals and an individualised plan of care. A peer support group that meets in the hospital, and a community outreach and reintegration group that meets in the community.</p>
Lapierre ²⁰	Not described directly Indirectly: to improve continuity of care between primary and tertiary health-care services	Outpatient consulting hours Outpatient consulting hours in a community centre	A primary care neurospinal nurse practitioner in collaboration with several care disciplines	<p>Managing, directing and providing comprehensive care in a collaborative multidisciplinary team. Activities are also referrals to other disciplines, consultation to other specialties, and collaboration with primary providers.</p> <p>When issues are clearly primary or rehabilitative in nature, patients are assessed in collaboration with the physiatrist.</p>

Remington ²¹	Not described	Outpatient consulting hours	A nurse practitioner in collaboration with a physician	Outpatient consulting hours, referrals to in-hospital services when appropriate, telephone contacts in case of emergent problems, and SCI teaching and counselling to patients, partners, and caregivers
Beer ²²	Not described directly Indirectly: Achieve the primary aim of a preventative nursing role Reduce the number of re-admissions to the spinal unit Help maintain social and domestic stability, and achieving independence for patients	Home visits	A home visiting nurse	Home visits to the family prior to discharge for support and re-teaching; Home visits after discharge to help with the re-introduction to home life, giving emotional and practical support, and identifying physical problems and directing patients to the appropriate specialist
Fine ²³	The assessment of architectural barriers in the place of residence and the need for equipment, and provision of direct patient care	Home visits	A registered nurse, a registered physical therapist, and a vocational rehabilitation counsellor	Predischarge home visits to assess architectural barriers and the need for equipment, and to provide education and support to family members Home visits at several intervals after discharge to provide direct care and education Following each home visit, a patient status report is distributed to local community health resources which provide ongoing care
Jones ²⁴	Prevention Facilitating difficult discharges Finding lost cases	Home visits	A nurse	Home visits to provide 'preventive' advice and instruction to patients, relatives, and district nurses. Sometimes these visits are combined with the visit of the family doctor, welfare officers, and/or district nurses
Cioschi ²⁵	Ensuring access of patients into an SCI system of care, so that expert, coordinated care can be delivered, complications can be minimised, and initial and long-term health-care costs can be reduced	Case management	A nurse clinician	A broad scale of interventions is described in the article, including medical/functional problem identification and early intervention, the coordination of care and resources, gate keeping functions that access appropriate health-care, identifying functional outcomes as they relate to the need for ongoing therapeutic interventions, and facilitating community reintegration
Beck ²⁶	To optimise individual and societal outcomes. To decrease the frequency of readmissions, and to enhance continuity of care	Mixed methods	Rehabilitation clinical nurse specialists	Education, assessment and intervention by means of a 1-day workshop, educational pamphlets, home visits and problem driven ongoing support during a 12-month period
Brown ²⁷	Medical follow-up, prevention and treatment of complications, ongoing support and education of the patient and his family	Mixed methods	Several care disciplines	Team reviews as often as is necessary for the first year after discharge, and then at yearly intervals Visits to home, visits to community facilities, and visits to work place Readmission in case of illnesses, injuries or other problems
Dinsdale ²⁸	Not described directly Indirectly: Re-integration and maintenance of physical well being	Mixed methods	Several care disciplines	Community based follow-up: Assessments by the public health nurse during the first week of discharge, at 6-month intervals for the first 2 years, and annually thereafter. A summary of the findings is communicated to the rehabilitation centre and the family physician

Table 1 Continued

<i>Author</i>	<i>Aim</i>	<i>Principle method</i>	<i>Care disciplines responsible</i>	<i>Content</i>
				<p>A home visit by the rehabilitation liaison nurse and the public health nurse in the first week postdischarge</p> <p>Procedures to organise medical care when necessary (by the rehabilitation team and/or primary health-care providers)</p> <p>A review in the spinal cord clinic at six weeks postdischarge for assessment by the physiatrist and other rehabilitation members</p> <p>Post discharge urological management by an urologist</p> <p>Providing expertise and support to the community health resources by the physiatrist and rehabilitation liaison nurse</p> <p>The comparison group received hospital-based follow-up: care provided by the physiatrist in cooperation with the family physician;</p> <p>Reviews by the physiatrist at 6 weeks and every 6–12 months thereafter</p> <p>Procedures to organise medical care when necessary (by the rehabilitation team)</p>
Duci ²⁹	Not described directly Indirectly: to reinforce the teaching, training, and support given to the patient and his family to help them make the transition to an independent, productive living situation	Mixed methods	Several care disciplines	<p>A home visit 2 or 3 weeks after discharge</p> <p>Outings for groups or individual patients (ie camping trip, sports game)</p> <p>Assessments of retraining capabilities and employment motivation</p> <p>Peer teaching and counselling</p> <p>Support to organise attendant care and regaining control of the patient's situation</p> <p>An assisted learning programme including educational videotapes which reteach skills and introduce new skills</p> <p>Promotion of networking with and among SCI persons in the community</p> <p>Consultation and education of community nursing agencies</p>
Lathbury ³⁰	To reinforce skills learned during hospitalisation, prevent secondary medical complications, and help with financial, social or accessibility problems	Mixed methods	A community re-entry specialist, a vocational rehabilitation counsellor, and a rehabilitation technician	<p>Extended care consists of two elements:</p> <p>(1) Home visits in which attention is paid to community involvement, recreation activities, transportation, mobility skills, accessibility issues, return-to-work or school opportunities, explaining procedures to caregivers or home health nurses, and providing on-site reviews of the home</p> <p>(2) An ongoing peer support programme</p>
Pollack ³¹	To foster independence and initiative, and to develop leadership skills. To enhance participants'	Mixed methods	Several care disciplines with coresponsibility of the participants	<p>(1) Informational sessions once a month, with topics being suggested by the participants and the committee</p>

Steinberg ³²	<p>knowledge base. To improve problem-solving skills and self-esteem. To develop one-on-one support, counselling and guidance. To facilitate community resource networking. To enhance socialisation</p> <p>Not described directly</p> <p>Indirectly: to ease the transition from hospital to home</p>	Mixed methods	Several care disciplines	<p>(2) Peer support groups once a month</p> <p>(3) A peer counsellor training and matching programme</p> <p>Nursing, social service, physical and occupational therapy and home health aides: by means of home visits, home health aid, and home therapy, instruction and education</p> <p>Hospital-readmission when necessary</p> <p>Reviews in the hospital at least once a year</p> <p>(1) A predischARGE home visit as soon after admission as possible to assess family strengths and weaknesses, the home, data about the community, and local health services</p> <p>(2) A postdischarge visit within 8 weeks after discharge to reassess the home programme and evaluate teaching and patient compliance. It consisted of a visit to patients' homes, their place of employment or school, and communication with the community health nurse. Teaching and counselling were carried out as necessary</p> <p>(3) Ongoing communication with patients, families and team members by phone calls and seeing patients in the clinics</p>
Warner ³³	To evaluate the effectiveness of the discharge plan and patient teaching and to provide interventions in case of problems	Mixed methods	A nurse	

Evaluation characteristics

Table 2 describes the design, number of patients, outcome measures, and outcomes of the studies that evaluated follow-up care programmes. In all, 16 out of the 24 follow-up care programmes had been evaluated to some degree.

Designs of evaluation In all, 11 evaluations were pre-experimental,^{10,12,16,20,22–25,30–32} three studies were quasi-experimental,^{13,17,18} and two studies were experimental in design.^{14,28}

Number of patients The number of patients included in the evaluation studies varied from 1 to 519 persons with SCI. Four evaluations of follow-up care did not mention the number of patients.^{20,22,24,31}

Outcome measures Several publications did not define the outcome measures in a methodology section.^{10,12,16,17,20,24,26,32} The outcome measures of these publications, mentioned in Table 2, have been derived from the descriptions of the results. Almost all studies used post-test-only measurements. In a few studies, partly pretest–post-test measurements were performed.^{16,26,32} Five types of outcome measures could be identified from the descriptions in the selected articles:

- (a) the incidence and/or improvement of secondary impairment(s),^{10,13,16–18}
- (b) health-care utilisation: for example, the number and duration of hospital readmissions, and the number of follow-up care contacts,^{10,12–14,17,22–24,26,28,32,33}
- (c) satisfaction with the care,^{12,20,26}
- (d) costs of the care,^{10,23}
- (e) other outcome measures: for example, self-reported health, independence, knowledge, and the level of functioning.^{12–14,18,24,26,28,31–33}

Results of the evaluations Most pre-experimental studies claimed positive effects of the follow-up care, although it was sometimes hard to derive this from the results presented. As a result of the pre-experimental design, the results of the evaluations are not included in the evaluation here.

The following effects were found in the quasi-experiments and experiments:

- (a) Incidence and/or improvement of secondary impairments: improvements were found in two^{17,18} of the three studies investigating the effects on this variable. In one of these studies¹⁷ there was no test for significance. Phillips¹³ found a higher incidence of pressure sores in the intervention group, but stated that the follow-up care appeared to improve ulcer tracking and management.

- (b) Health-care utilisation: three^{14,17,28} out of four studies investigating the effects on this variable found a decline of health-care utilisation, although no information was provided about the statistical testing of the findings. The remaining study¹³ reported more hospitalisations in the intervention groups compared with the comparison group, although this difference was not significant.
- (c) Other outcomes: Phillips¹³ found a higher postinjury employment rate in the intervention group, although this difference was not significant. Dunn¹⁸ reported significantly better subjective health, independence and less depression in the experimental group. In another study Phillips¹⁴ found, at 1-year post-discharge, significantly higher scores of the quality of well-being in both the intervention groups. On the other hand, at one-year post-discharge, the video group had more depressive symptoms than the telephone or standard care group. Dinsdale²⁸ found no differences with respect to ADL, integration (school and work), and needs detected at follow-up. However, more emotional, housing, vocational and health agency support was used in the intervention group.

Discussion

The literature search provided only a small number of descriptions of follow-up care programmes. The description of the content of these programmes sometimes was rather scattered, vague and brief. Five methods of follow-up care were identified: telemedicine, outpatient consulting hours, home visits, case management, and mixed types of follow-up care.

In all, 16 out of the 24 follow-up care programmes have been evaluated to some degree. Health-care utilisation was the most frequently studied outcome measure, followed by the incidence and/or improvement of secondary impairment(s). Only a small number of studies paid attention to the effects of follow-up care on the satisfaction with the care, the cost of care, health, and independence. In general, the quality of the evaluation studies was low. Most evaluations were pre-experimental in design. Only three were quasi-experimental, and two were experimental in design. Although several studies found positive effects, it was not possible to draw general conclusions on the effect of follow-up care on the occurrence of secondary impairments, well-being, the quality and costs of care. It can be concluded that the effectiveness of follow-up care programmes for persons with SCI remains far from proven.

The results of this review may, however, be limited for several reasons. First, it may be questioned whether all possible relevant articles were detected. However, we searched the MEDLINE and CINAHL databases, made use of a combination of MeSH (indexing terms) and text words that covered a wide range of the research field, tried other search strategies too, and studied all

Table 2 Evaluation characteristics

<i>Author</i>	<i>Design</i>	<i>N</i>	<i>Outcome measures*</i>	<i>Outcomes^a</i>
Mathewson ¹⁰	Pre-experiment	1	a,b,c	^a After 6 months, the wound was stable and manageable ^{b,c} Less time and costs compared to regular care. Pressure ulcers surgery was avoided
Phillips ¹²	Pre-experiment	11	b,d ^c A description of problems mentioned in the initial telephone call after discharge	^b An average of 10 video calls and six telephone calls per client with an average length of 23 min. The intervention lasted to 32 weeks ^d Positive overall impressions ^e In all, 10 problems were mentioned by 11 patients. Experience about the use of a videophone and the appropriate number of video-consultations to offer
Phillips ¹³	Quasi-experiment (matching)	Video group 12 Standard care 10 Telephone group 13	a,b ^e Employment status	^a The video group had the greatest number of pressure ulcers. The telehealth intervention improved ulcer tracking and management ^b Small differences between the video and telephone groups ^e The video group had the lowest preinjury rate of employment and the highest postinjury rate of employment. No significant differences at $P < 0.05$
Phillips ¹⁴	Experiment	Video group 36 Telephone group 36 Standard care 39	b ^e Employment status, a self-report measure of handicap, quality of life (by means of quality of well-being, QWB) and depression (by means of the Centre for Epidemiologic Studies Depression scale, CES-D)	^b Mean annual hospital days were 3.00 for the video group, 5.22 for the telephone group, and 7.95 for the standard care group ^e QWB scores did not differ significantly at the end of the intervention period. At year 1 postdischarge, scores were significantly higher for both the intervention groups compared to standard care Depressive symptoms declined for all three groups, at one year postdischarge the video group had the most of depressive symptoms
Barber ¹⁶	Pre-experiment	17	a	^a In all, 11 patients responded sufficiently to counselling
Dover ¹⁷	Quasi-experiment	Intervention group 135 Comparison group 10	a,b	^{a,b} The incidence of pressure sores and readmissions were higher in the control group. No testing for significance
Dunn ¹⁸	Quasi-experiment	Intervention group 235 Comparison group 136	^a By means of the Secondary Conditions Screening Instrument ^e Self-reported health, independence, and depression (by means of the Check Your Health Questionnaire)	^a There were similar secondary conditions in the two groups, but higher frequency and severity in the comparison group ^e Significant better subjective health, independence, and less depression in the experimental group compared to the comparison group

Table 2 Continued

Author	Design	N	Outcome measures*	Outcomes ^a
Lapierre ²⁰	Pre-experiment	?	^d By means of the Out-Patient Satisfaction Questionnaire	^d In all, 93% of the respondents were either satisfied or very satisfied
Beer ²²	Pre-experiment	?	^b	^b There was a 34% decrease in the incidence of hospitalisations for pressure sore treatment from the years 1971–1973 to the period 1977–1979 and bed occupancy per year for their treatment decreased by 30 per cent. There were only a small number of hospitalisations for the treatment of urinary tract infections
Fine ²³	Pre-experiment	519 in 5 years	^{b,c}	^{b,c} Descriptive information regarding the type, amount and costs of care, and the number of patients who completed the programme or not. The authors had the impression that the care is a valid concept, although the most appropriate role for the team still remained to be clarified. It was their belief that direct care first should be provided before assuming responsibility for educating other health professionals
Jones ²⁴	Pre-experiment	?	^b ^e The number of cases in which the programme facilitated difficult discharges (persons with high-level tetraplegia), and allowed the discovering of equipment and house adaptation needs	^b Since the home visiting began, there were fewer readmissions for sores, and the average length of stay for sore treatment declined from 6 to 3.5 months
Beck ²⁶	Pre-experiment	A total of 25 workshop and home visit participants of whom nine were consumers	^{b,d} ^e Participant's knowledge perception	^e The programme facilitated discharge in 22 difficult cases and often allowed discovery of the need for various equipments ^b Two consumers asked for support, two were hospitalised for elective bladder surgery ^d High satisfaction (87–100%) with the programme
Dinsdale ²⁸	Experiment	Community-based programme, 12 Hospital-based programme, 11	^b ^e Physical well-being, activities of daily living, psychological functioning, social vocational functioning and needs detected at follow-up	^e Increased knowledge perception on six out of 17 items immediately after the workshop ^b Seven readmissions in the intervention group against 13 in the control group ^e Both groups were equally functioning with respect to ADL More patients in the intervention group received emotional support Both groups had about the same rate of integration More housing, vocational, and health agency support in the intervention group The two programmes were roughly equivalent in identifying potential problems
Pollack ³¹	Pre-experiment	?	^e The effectiveness of the programme (not elaborated)	^e 100% of the participants found the programme to be helpful and 85.7% expressed that the programme is meeting expectations

Steinberg ³²	Pre-experiment	In all, 31 in 9 years	<p>^b</p> <p>^cThe level of functioning after discharge, compared to the level of functioning at discharge, reasons for discharge from home care</p>	<p>^bThere were 179 hospitalisations. In all, 11 patients were admitted due to pressure sores. A total of 18 patients who were on home care for more than one year spent from 0.8 to 27.4% of their home care days in the hospital. Patients were hospitalised more promptly but for briefer periods</p> <p>^cMost patients retained the level of functioning of the moment of discharge. Of the 31 patients, 21 were discharged and 10 were still on the programme. Complications were recognised before they became major. Home care helped to keep families intact</p> <p>^b61% of the patients were hospitalised at least once after discharge</p> <p>^cThe team members agreed with the role expectations</p> <p>Of the patients, 91% had no problems for which they thought they had not been prepared. A total of 21% of the patients made suggestions to make the transition to home easier. In all, 63% had suggestions for other patients. Of the patients, 42% stated to have had suggestions that may have prevented problems</p> <p>Patients perceived relatively few problems and felt prepared for returning to the home and the community. The authors felt that the follow-up programme was the major reason for these findings</p>
Warner ³³	Pre-experiment	In all, 40 in 1 year	<p>^b</p> <p>^cThe team members' agreement with the follow-up coordinator's role expectations. Address status, employment status, suggestions that might have made transition from rehabilitation centre to home easier, and suggestions for other patients</p>	

*In the 'outcome measures' column:

^aThe incidence and/or improvement of secondary impairment(s)

^bHealth care utilisation

^cCosts of the care

^dPatients' satisfaction with the care

^eOutcome measurement as described in the table

**In the 'outcomes' column the 'superscript letters' also refer to the above mentioned outcome measures, per outcome measure the results are given

publications initially selected by at least two of the three researchers, including publications without abstracts. We are therefore reasonably confident that we did not miss relevant publications that should have been included in this review.

Second, the review may possibly be subject to 'publication bias', implying that several existing follow-up care programmes and their evaluations might not have been described in the literature. Since we have got to know several follow-up programmes in practice that were not included in our study, we assume the presence of publication bias.

Thirdly, 18 out of the 24 publications included in this study were from the USA, two were from Canada,^{20,28} two from the UK,^{17,24} and two from Australia.^{22,27} Therefore, the results cannot be translated to other countries. The obvious difference between the number of follow-up care programmes performed in the USA compared to those in other parts of the world, such as North-West Europe, may be explained by the fact that the content of follow-up care programmes in Europe might have not been communicated in English or German. Another reason for the high percentage of US follow-up care programmes may be the difference regarding the duration of in-patient rehabilitation. Since the duration of in-patient rehabilitation in the USA is relatively short, the need for follow-up care in the USA may be higher.

All this contributes to the most important conclusion of this review: there is a need for the development, the publication and the well-designed evaluation of follow-up care programmes for persons with SCI. We encourage rehabilitation centres, specialised in the rehabilitation of persons with SCI, to take the initiative to organise follow-up care, preferably in cooperation with primary care professionals and/or patient organisations. Since primary care professionals rarely have sufficient knowledge and experience about the specific care persons with SCI need (due to the low prevalence of persons with SCI), it is important that the expertise of specialised rehabilitation centres is in some way or another available for persons with SCI living in the community and that these centres should take the initiative in organising follow-up care. Cooperation with primary care professionals is preferable, since they are the persons first and foremost to deliver care at home. From our review we learned that follow-up care programmes vary widely with regard to aim and methods. To facilitate comparisons of design and results of such programmes, we propose a rough classification system, based on three dimensions:

1. Classification according to the aim of follow-up care:

- specific aim like preventing or treating one or more secondary complications;
- generic aim like the promotion of quality of life, participation and community reintegration;
- combination of the aims mentioned above.

2. Classification according to the method of follow-up care:

- preventive activities directly aimed at individual patients or patient groups;
- therapeutic activities directly aimed at individual patients or patient groups;
- activities aimed at the promotion of continuity of care;
- combination of the methods mentioned above.

3. Classification according to the localisation of the care:

- at the patient's home;
- in the rehabilitation centre;
- both at the patient's home and in the rehabilitation centre making use of communication technologies;
- combination of methods mentioned above.

With regard to the evaluation of follow-up care programmes we think it is important to evaluate the follow-up care with regard to its effectiveness (effects on the prevalence on secondary impairments). Furthermore, attention should also be paid to the effects regarding the efficiency (costs and health-care utilisation) and the effects on quality of care (satisfaction and continuity).

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