

Primary care of people with spinal cord injury

Scoping review

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Abstract

Objective To perform a scoping review of the empirical evidence between 1980 and 2009 regarding primary care for adults with spinal cord injury (SCI).

Data sources Peer-reviewed journals were searched from 1980 to 2009 using CINAHL, PubMed-MEDLINE, EMBASE, PsycINFO, Social Sciences Abstracts, and Social Work Abstracts.

Study selection The key word-driven electronic search identified 42 articles on primary care and SCI. Inclusion criteria narrowed the set to 21 articles that were published in English, that had a sample size of greater than 3, and that offered empirical analysis.

Synthesis Approximately 90% of people with SCI identify family physicians as their regular doctors; 63% have SCI specialists. People with long-term SCI develop complex rubrics for navigating their personal health care systems. There is conflicting evidence about the effectiveness of outreach programs for maintaining health and preventing complications following SCI. Regular follow-up by specialized teams and annual comprehensive health examination are supported by the evidence. The research shows a high level of consistency in identifying the most common issues raised by people with SCI in primary care, most of which are related to disability—specifically, secondary complications such as bowel or bladder dysfunction and pain. There is also good evidence that many general health issues require attention in this population, such as bone density problems, depression, and sexual and reproductive health issues. There is level 4 and 5 evidence for unmet health needs among individuals living with SCI in the community. Despite patients with SCI being high users of primary care and health services in general, the evidence suggests that the information needs of these patients in particular are poorly met.

Conclusion A robust system of primary care is the best assurance of good health outcomes and reasonable health service use for people with SCI, including annual comprehensive examination, appropriate specialist use, and attention to accessibility and unmet needs.

In most typical primary care practices there are only a handful of patients with spinal cord injury (SCI), and there is considerable uncertainty among family physicians about how to provide them with an optimal standard of care.¹⁻⁵ Approximately 1400 new SCIs occur in Canada every year, and although prevalence estimates are highly variable, it is safe to assume that at least 50000 Canadians live with SCI.⁶ At these rates, the average family medicine case load would have only 1 or 2 patients at a time with SCI.

Family physicians play an important coordinating role, acting as a link between patients with SCI and multiple health care providers.⁷ Primary care is good, economical, holistic care, but the literature suggests that family medicine does not serve patients with SCI as well as other patients.⁸⁻¹¹

The objective of this study is to describe the empirical evidence currently available regarding primary care for adults with SCI. The scoping study is an emerging method of literature synthesis, defined as a way of mapping key concepts within a research area by assembling multiple sources and types of evidence.¹² The emphasis of a scoping study is on comprehensive coverage, rather than on a particular standard of evidence. Arksey

KEY POINTS The existing literature suggests that optimal primary care for patients with spinal cord injury might include routine annual comprehensive health evaluation; multidisciplinary follow-up to address issues that accompany long-term disability; accessible premises that permit full examination of presenting health complaints; access to disability-specific expertise in the form of specialists, regarding common secondary complications such as pain and bowel and bladder complications; and awareness of areas in which there are often unmet needs, such as psychological concerns, sexual and reproductive health, and lifestyle issues.

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and O'Malley¹² define 4 reasons to undertake a scoping review. This review fulfills their third purpose: to summarize and disseminate research findings to key stakeholders.

For the purposes of this study, *primary care* is defined according to Health Canada's definition, as "health services provided at the first point of contact with the health care system ... including health promotion, illness and injury prevention, and diagnosis and treatment of illness and injury."¹³ While primary care can involve a number of service providers (medical and allied health), most people still think of their family doctors first when seeking primary care.¹⁴

DATA SOURCES

Peer-reviewed journals were searched for the interval between 1980 and 2009 using the following electronic search engines: CINAHL, PubMed-MEDLINE, EMBASE, PsycINFO, Social Sciences Abstracts, and Social Work Abstracts. The process of study selection began with a key word-driven electronic search. The following key words were combined pairwise, with 1 from the first set and 1 from the second set for each search: *spinal cord injury, paraplegia, quadriplegia, tetraplegia, secondary complications* and *primary care, family physician, family practice, health promotion, evidence-based practice, best practice, clinical guidelines*.

Study selection

Articles were included if they were published in English and they focused on SCI, or at least included participants with SCI. Abstracts were reviewed by research staff and at least 1 investigator in the selection process. The investigative team comprised experts in family medicine, disability, rehabilitation, and knowledge translation, all of whom had previous experience with the scoping review methodology.¹⁵

The review process identified 42 items. To further focus the search, articles were read in their entirety by at least 2 of the authors¹⁵ and were excluded if they had a sample size of less than 3, were opinion or editorial pieces, or did not permit SCI-specific data to be identified. Based on these criteria, 21 articles were excluded and 21 articles remained that dealt specifically with issues of access to and quality of primary care for people with SCI (**Table 1**).¹⁶⁻³⁷

The final set of articles was reviewed by at least 2 of the researchers for themes, issues, and levels of evidence. **Table 2**¹⁶⁻³⁸ summarizes the evidence, based on 3 factors:

- Level of evidence was assessed according to Sackett and colleagues.³⁸
- Methodologic rigour was evaluated according to Downs and Black on a scale from 1 to 20, with higher

scores corresponding to higher levels of methodologic rigour.³⁷

- Sample size was noted as an indication of the precision of the estimates generated in the study.

Of the 21 articles selected, only 1 resulted in level 2 evidence (quasi-experimental studies such as prospective studies, non-randomized comparison group and observational studies); 1 offered level 3 evidence (pre-experimental studies, such as uncontrolled studies, historical and retrospective reviews); 6 offered level 4 evidence (observational studies including posttest-only designs, case series, secondary analyses of administrative data); and 13 surveys provided level 5 evidence (surveys, case reports, single-subject studies).

There were no studies that offered level 1 evidence (ie, randomized clinical trials). Eleven studies used large samples (more than 100 participants), 8 used medium-sized samples (31 to 100), and 2 used small samples (30 or fewer). Eleven took place in the United States, 6 in Europe (including the United Kingdom), 3 in Canada, 2 in Australia, and 1 in India.

SYNTHESIS

Use and access

Donnelly and colleagues²¹ and Bockenek³³ agree that most people with SCI (approximately 90%) identify family physicians as their regular doctors. They show that people with long-term SCI develop complex rubrics for navigating their personal health care systems. Glickman and associates,³⁴ in a survey of primary care providers in England, found that on average, patients with SCI attended their clinics 4 times per year, with an additional 4.5 home visits per patient made by the family doctors. Munce and colleagues,¹⁷ focusing on the Canadian context, found that very high use of health care resources among patients with SCI (more than 50 visits per year) was related to being older than 70 years of age, having substantial complications, and living in a chronic care facility.

Bockenek³³ and Warms³⁶ found that more than 50% of patients with SCI considered their physiatrists to be their primary care physicians. Donnelly and colleagues²¹ found that 63% of their sample from the United States, United Kingdom, and Canada had SCI specialists, 56% had both SCI specialists and family doctors, and 1% had neither. In a survey of physiatrists treating patients with SCI, Francisco and colleagues³⁵ found that only 40% of physiatrists were willing to assume the primary care role, and only 38% thought that their residency training had adequately equipped them to assume that role.

Table 1. Summary of the 21 articles included in the scoping review of primary care and SCI

| STUDY DETAILS | METHODS | OUTCOME |
|--|--|--|
| Ashe et al, ¹⁶ 2009; Canada; D&T score* = 11; survey; N = 22 | Population: 22 physiatrists treating patients with SCI Treatment: None Purpose: To assess opinions about bone health and treatments among physiatrists Outcome measures: A survey assessing opinions and practice patterns relating to bone health after SCI | <ul style="list-style-type: none"> • 86% of physiatrists considered bone health after SCI to be an important issue • Most physiatrists reported that pharmacologic treatments were most beneficial, whereas rehabilitation modalities had lower support for effectiveness |
| Munce et al, ¹⁷ 2009; Canada; D&T score = 12; observational; N = 559 | Population: 559 adult (136 female) patients with SCI, > 1 y after discharge from acute care Treatment: None Purpose: To examine physician use from various Ontario health databases for the years 2003 to 2006 Outcome measures: Physician use, including FP, specialist, and ED; Charlson index (comorbidity) and Rurality Index for Ontario | <ul style="list-style-type: none"> • Women had a higher number of FP visits; men had a higher number of specialist visits (physiatrist) • Older (≥ 70 y) age (OR = 3.64), discharge to chronic care (OR = 3.62), and in-hospital complications (OR = 2.34) associated with >50 visits/y • Younger age (OR = 0.19) and direct discharge to chronic care (OR = 11.52) were associated with ≥ 50 specialist visits/y • Rurality Index for Ontario results predicted ≥ 2 visits to the ED (OR = 2.16) |
| Van Loo et al, ¹⁸ 2010; Netherlands; D&T score = 12; survey; N = 453 | Population: 453 adults with SCI; average 13 y after injury Treatment: None Purpose: To determine care and needs related to secondary conditions, and to determine if the secondary conditions were preventable Outcome measures: Questionnaire on frequency of SCI-related contacts with health professionals in past year, secondary conditions, and how the condition could have been prevented | <ul style="list-style-type: none"> • 77% had SCI-related contact with their general physicians, 57% with physiatrists, and 65% with other specialists • On average, participants mentioned 8 secondary conditions, including bladder and bowel regulation, pain, spasms, sexual problems, and pressure sores • 50% of the pressure sores and 25% of the bladder, bowel, and sexual problems could have been prevented according to the participants • 72% indicated the need for additional care of secondary conditions |
| Bloemen-Vrencken et al, ¹⁹ 2007; Netherlands; D&T score = 15; prospective controlled study; N = 62 | Population: 62 adults with SCI in first year after discharge (31 experimental and 31 control subjects) Purpose: To evaluate nurse-led outreach from rehabilitation to primary care Treatment: Transmural care (nurse as a liaison between patient, primary care, and rehabilitation centre) in addition to usual follow-up care Control: Usual follow-up including periodic outpatient visits to rehabilitation centre Outcome measures: Prevalence of pressure sores and urinary tract infections; number and duration of readmissions to hospital and rehabilitation centres owing to pressure sores or bladder and bowel problems in the first year after discharge | <ul style="list-style-type: none"> • No significant difference seen in prevalence of pressure sores and urinary tract infections between groups • No significant differences seen in readmission rates between groups • Quality of follow-up care experienced not significantly different between groups |
| Booth and Kendall, ²⁰ 2007; Australia; D&T score = 9; observational; N = 40 | Population: 40 adults with new SCI discharged to non-metropolitan areas Purpose: To evaluate effectiveness of TR for people with SCI in rural Australia Treatment: Home-based TR program; multidisciplinary team allowed completion of rehabilitation in real-world environment Outcome measures: Benefits and challenges of TR programs | <ul style="list-style-type: none"> • Extra time and resources allowed TR staff to coordinate with LCPs, increase family involvement, enhance social and community supports, and ensure availability of specialist support for equipment, mobility, and adjustment problems |
| Donnelly et al, ²¹ 2007; Canada, United States, and United Kingdom; D&T score = 10; survey; N = 373 | Population: 373 individuals with SCI, average 36 y after injury Treatment: None Purpose: To describe use, accessibility, and satisfaction with primary and preventive health care services; to compare across Canada, United States, and United Kingdom Outcome measures: HCQ, PSHCPS | <ul style="list-style-type: none"> • 93% had FPs, 63% had SISs, and 56% had both; 36% had only FPs, 6% had only SISs, and 1% had no doctor at all • Issues of sexual health, alcohol use, community functioning, and emotional health were not addressed for > 70% of participants • The highest use of FPs was for pain (86%, $P < .05$) and fatigue (84%, $P < .05$); the highest use of SISs was for routine rehabilitation follow-up (91%, $P < .05$) • FPs showed problems with physical accessibility of office and equipment • Satisfaction was rated as 74% for FPs and 76% for SISs |

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| <p>Gottkovskiy et al,²² 2007; United States; D&B score = 12; survey; N = 82</p> | <p>Population: 82 patients with SCI, average 7 y after injury; mean (SD) age 42 (14) y Treatment: None Purpose: To examine the perceived information needs of individuals with chronic SCI and determine the factors that influence these needs Outcome measures: Questionnaire on access to health information since inpatient discharge (23 domains)</p> | <ul style="list-style-type: none"> • Information needed on aging (73%) and SCI research (66%) • ≥ 16% of the sample reported information needs in each of the 23 domains • Ethnic minority participants endorsed considerably more information needs |
| <p>Collins et al,²³ 2005; United States; D&B score = 16; survey; N = 853</p> | <p>Population: 853 veterans with SCI; mean age 59 y Treatment: None Purpose: To assess patient satisfaction with the annual CPHE Outcome: Survey of satisfaction with CPHE, whether needs were met, what respondents valued about the examination, and health concerns they would like to see addressed</p> | <ul style="list-style-type: none"> • 76% of respondents had completed CPHEs within the previous year • Main reason was to get medication and supplies refilled and to talk to doctors • Topics discussed during the CPHE were muscle strength and weakness, bladder care, chronic pain, digestion and bowel care issues, and equipment problems • Satisfaction with the CPHE was 81% • Completion of the CPHE was related to other health care use and having health needs met |
| <p>Goetz et al,²⁴ 2005; United States; D&B score = 13; posttest; N = 4432</p> | <p>Population: 4432 veterans with SCI; mean age 54 y Purpose: To evaluate effect of CPG on bowel care Treatment: CPG for management of neurogenic bowel; implementation strategies included practice tools such as reporting forms and flow sheets Outcome measures: Adherence measured before implementation (T1), after publication (T2), and after targeted dissemination and implementation strategies (T3)</p> | <ul style="list-style-type: none"> • Overall adherence to recommendations did not change between T1 and T2 • Statistically significant increase in adherence for 3 of 6 recommendations from T2 to T3 ($P < .001$) • Publication alone did not alter adherence; targeted implementation increased adherence |
| <p>McDermott et al,²⁵ 2005; United States; D&B score = 15; observational; N = 35 SCI patients</p> | <p>Population: 35 adults with SCI, mean age 35y; total sample 3636 (1552 with disability, 2084 controls) Treatment: None Purpose: To determine rate of depression among individuals with disabilities Outcome measures: Review of computerized medical records from 1990 to 2003 and companion paper records</p> | <ul style="list-style-type: none"> • Patients with disabilities have significantly higher rates of depression ($P = .019$) • 28.6% of people with SCI were found to be depressed • Trauma (SCI and TBI) related to significantly earlier onset of depression compared with controls ($P = .0007$) • By age 50 y, 16% to 17% of patients with trauma had depression; by age 60 y, 45% of trauma patients had depression, compared with 18% of controls |
| <p>Williams,²⁶ 2005; United Kingdom; D&B score = 4; survey; N = 31</p> | <p>Population: 31 adults with SCI seen at a community clinic Purpose: To evaluate the effectiveness of follow-up clinics to promote improved health information Treatment: Nurse-led clinic; holistic nursing assessment and peer support Outcome measures: Effectiveness of nurse-led services</p> | <ul style="list-style-type: none"> • Participants reported benefits from nurses' up-to-date knowledge of specific bowel or bladder problem-solving approaches • Participants perceived nurses to be more understanding and better informed; found sessions informative, practical, and helpful |
| <p>Prabhaka and Thakker,²⁷ 2004; India; D&B score = 8; posttest; N = 546</p> | <p>Population: 546 adults with SCI living in communities across India Purpose: To evaluate the effects of long-distance home visiting as an alternative to clinical follow-up for rural areas Treatment: A home visit program with an outreach team (counselor, surgeon, physiotherapist, occupational therapist, prosthetist, orthotist, social worker, nurse); aim to decrease the rate of hospital readmissions Outcome measures: Complete assessment including bladder and bowel function, sexual rehabilitation, problems faced by SCI patients and family, social relations, available support, and opportunities for vocational rehabilitation</p> | <ul style="list-style-type: none"> • Home visit program decreased the number of readmissions, improved status of rehabilitation, and raised quality of care for patients |

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| Beatty et al, ²⁸ 2003; United States; D&B score = 14; survey; N = 800 (169 with SCI) | Population: 169 adults with SCI; total sample 800 Treatment: None Purpose: To survey patterns of need and access to specific health care services, and factors identified as predictors of access Outcome measure: 80-item self-report questionnaire on perceived need for and access to PCP, SC, PR, AE, PM; analyzed by health plan (fee-for-service and managed care) | <ul style="list-style-type: none"> • Overall need for health services: 62.7% reported a need for PCP, 57.4% for SC, 39.1% for PR, 69.2% for AE, and 94.1% for PM • Need vs actual receipt of services: Only 67% of needed PCP care was received, 75.3% of SC, 40.9% of PR, 69.2% of AE, and 93.1% of PM • Factors affecting access: health plan type, condition, health status, severity, coverage, income, age. No differences were found across sex and region of residence |
| Beck and Scroggins, ²⁹ 2001; United States; D&B score = 6; posttest; N = 19 | Population: 3 adults with quadriplegia and 16 long-term health care providers Purpose: To evaluate an interdisciplinary education and support program Treatment: Health Maintenance Education Program including interdisciplinary workshop, collaborative home visit for individualized assessment, education and intervention, ongoing support Outcome measures: Program evaluation forms | <ul style="list-style-type: none"> • Significant increase in knowledge of prevention of respiratory complications ($P < .05$), prevention and treatment of autonomic dysreflexia ($P < .05$), prevention of spasticity ($P < .01$), reportable symptoms ($P < .01$), effects of aging ($P < .001$), availability of community resources ($P < .01$) |
| Vaidyanathan et al, ³⁰ 2001; United Kingdom; D&B score = 10; survey; N = 128 | Population: 128 SCI patients attending regional follow-up clinic Treatment: None Purpose: To assess need for information about changes in condition; to assess potential for information to cause anxiety to patients, relatives, or caregivers Outcome measures: 28-item survey | <ul style="list-style-type: none"> • 83% of patients wished to receive written information following clinic visits • 93% wished for information about changes in their medical conditions after readmission to the spinal unit • 90% wanted copies of MRI results with interpretation and wanted them shared with their GPs • 95% thought that written information would not cause needless anxiety |
| Cox et al, ³¹ 2001; Australia; D&B score = 9; survey; N = 54 | Population: 54 adults with SCI, mean age 39 y Treatment: None Purpose: To assess the nature and extent of unmet health needs Outcome measures: Telephone survey of need for specialist multidisciplinary outreach service, most important barriers to meeting needs, preferred service delivery options | <ul style="list-style-type: none"> • 25% indicated high or very-high need for specialist outreach services • Barriers to meeting health needs included limited local expert knowledge (81%), inadequate funding (56%), complicated process or service fragmentation (31%) • Preferred mode of service delivery: telephone advice (79%) or home visiting (43%) |
| Oshima et al, ³² 1998; United States; D&B score = 9; survey; N = 44 | Population: 30 IM and 14 ObGyn residents Purpose: To assess knowledge and comfort of medical residents to provide sexual and reproductive care to patients with SCI Treatment: None Outcome measures: Students were asked how they would treat a hypothetical case of a pregnant woman with quadriplegia; questions addressed conducting an examination, dealing with spasticity, transferring the patient to the examination table, self-rating of comfort level in managing the patient | <ul style="list-style-type: none"> • 75% of IM and 67% of ObGyn residents would conduct a pelvic examination • 53% of IM and 64% of ObGyn residents would ask staff to lift the patient on the table; 21% of ObGyn residents reported access to an elevating table • 40% of IM residents said they did not have the necessary resources or knowledge • 17% of IM and 14% of ObGyn residents did not know how to manage spasticity; 36% expressed concern about spasticity • 43% would refer to physiatry • Most reported comfort level as neutral to uncomfortable |
| Bockeneck, ³³ 1997; United States; D&B score = 8; survey; N = 144 | Population: 144 SCI outpatients Treatment: None Purpose: To survey if primary care needs of outpatients with SCI were met Outcome measures: Self-reported survey assessing the ability of the local community to provide primary care services, and to determine whether additional services were needed from a rehabilitation facility | <ul style="list-style-type: none"> • 50% of SCI outpatients considered their rehabilitation physician to be their PCP • 48% had general medical problems treated by GPs • 96% of SCI patients reported that their physicians' offices were accessible • 90% had no difficulty receiving medical care in the community • 51% of SCI patients preferred obtaining all medical care at a rehabilitation facility |

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| <p>Glickman et al,³⁴ 1996; England; survey; D&B score = 6; N = 139</p> | <p>Population: 139 GPs with SCI patients Treatment: None Purpose: To examine the workload and common problems facing primary care teams in SCI management Outcome measures: Mailed survey inquiring about annual number of consultations with the patient; prevalence of gastrointestinal, urologic, and dermatologic problems, pain, and spasticity</p> | <ul style="list-style-type: none"> • Average annual consultation rate with GP in surgery = 4.03; GP home visit = 4.57; other team member in surgery = 0.56; other team member home visit = 50.94 • 78.5% of SCI patients had multiple current health problems; 11.5% had 0 problems; 10.1% had 1 problem • 72% had urologic problems; 49.6% had bowel issues; 41.7% had skin problems; 65.5% had spasticity; 55.4% had pain • 29.5% were offered psychological or social counseling |
| <p>Francisco et al,³⁵ 1995; United States; D&B score = 11; survey; N = 104</p> | <p>Population: 54 physiatrists and 50 physiatry residents Treatment: None Purpose: To determine physiatrists' and residents' opinions on their competency, qualification, and desire to provide primary care for patients Outcome: Self-report questionnaire on level of training regarding primary care provision by physiatrists; reasons why or why not to provide primary care; disabled patients that should receive primary care by physiatrists</p> | <ul style="list-style-type: none"> • 53% believed physiatrists were competent to provide primary care; only 40% were willing to assume the role • 38% believed that physical medicine and rehabilitation residency programs adequately trained physiatrists in primary care • Conditions for which most respondents believed that primary care should be provided by physiatrists were SCI (60%) and brain injury (51%) |
| <p>Warms,³⁶ 1987; United States; D&B score = 9; survey; N = 59</p> | <p>Population: 59 adults with SCI, at least 2 y after injury; age 21 to 60 y Treatment: None Purpose: To survey health care received by individuals with SCI and to describe what health care services are desired Outcome measures: A self-reported survey assessing source of health care, content of care, and health care services desired but not obtained</p> | <ul style="list-style-type: none"> • 54.2% reported consulting rehabilitation medicine physicians in the past year; 44% consulted FPs in the past year • 80% of issues raised were related to disability • 52.9% discussed bladder or kidney problems, 47.1% discussed pressure sore prevention, 23% reported spasticity, and 23% discussed bowel issues • Unmet needs were reported for health promotion, fitness, and diet |

AE—assistive equipment, CPG—clinical practice guideline, CPHE—comprehensive preventive health evaluation, ED—emergency department, HCQ—Health Care Questionnaire, IM—internal medicine, LCP—local care provider, MRI—magnetic resonance imaging, ObGyn—obstetrics and gynecology, OR—odds ratio, PCP—primary care physician, PM—prescription medications, PR—physical rehabilitation, PSHCPS—Patient Satisfaction with Health Care Provider Scale, SC—specialist care, SCI—spinal cord injury, SIS—spinal injury specialist, TBI—traumatic brain injury, TR—transitional rehabilitation.

*Methodologic rigour score, evaluated on a scale from 1 to 20, with higher scores corresponding with higher levels of methodologic rigour; Downs and Black, 1998.³⁷

For people with SCI, access issues—the simple ability to enter the practice and receive an appropriate standard of care—cause more than delays and inconvenience; inadequate access might actually prevent care. Physical accessibility of the office and equipment is often an issue.²¹ However, the most prevalent impediment to accessible primary care is the need for specialized expertise in order to adequately serve as the first-line provider for patients with SCI. In Australia, Cox and associates³¹ found that 81% of people with SCI living in the community reported limited local provider expertise in SCI. Bockenek³³ and van Loo et al¹⁸ found that patients preferred specialist care, and were happiest to receive their follow-up care from rehabilitation specialists.

A number of approaches have been proposed in the literature for enhancing access to and quality of primary care for people with SCI. Goetz and colleagues²⁴ show that clinical guidelines for specialized primary care can improve outcomes for people with SCI. There is conflicting evidence for outreach, in which expert providers (usually from an institutional rehabilitation

setting) reach out to supplement the resources of community primary care settings. Booth and Kendall²⁰ showed that specialized multidisciplinary outreach enhanced successful transition to the community. On the other hand, Bloemen-Vrencken and associates¹⁹ saw no difference in complications, readmissions, or quality of primary care in an outreach program from rehabilitation to primary care. Participants in a nurse-led clinic for bowel and bladder care reported that more up-to-date and practical information was obtained from nurses than from their usual primary care providers.²⁶ Beck and Scroggins²⁹ found significant ($P < .05$) increases in knowledge and skills with an educational intervention aimed at people with quadriplegia. Prabhaka and Thakker²⁷ showed a decrease in readmissions, and an increase in functional status and quality of care, using a home visiting program. Cox and colleagues³¹ found that home visits and telephone consultations were preferred methods for increasing accessibility to primary care.

Satisfaction was high (about 75%) with the quality and accessibility of primary care,²¹ particularly the

Table 2. Summary of the evidence from selected studies of primary care and SCI

| FINDING* | REFERENCE | D&B SCORE [†] | N |
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| There is level 2 evidence that ... | | | |
| <ul style="list-style-type: none"> An outreach program (transmural care—nurse liaison from rehabilitation to primary care) does not appear to be effective in reducing pressure sores, urinary tract infections, or hospital readmission rates | Bloemen-Vrencken et al, ¹⁹ 2007 | 15 | 62 |
| There is level 3 evidence that ... | | | |
| <ul style="list-style-type: none"> Depression rates are higher and onset is earlier among individuals with disabilities, especially traumatic-onset disabilities, such as SCI, compared with controls | McDermott et al, ²⁵ 2005 | 15 | 35 |
| There is level 4 evidence that ... | | | |
| <ul style="list-style-type: none"> An annual comprehensive preventive health evaluation conducted at the SCI centre is related to improved health care use and having health, psychosocial, and equipment needs met | Collins et al, ²³ 2005 | 16 | 853 |
| <ul style="list-style-type: none"> Clinician adherence to bowel and bladder guidelines improves with a targeted implementation plan | Goetz et al, ²⁴ 2005 | 13 | 4432 |
| <ul style="list-style-type: none"> GP use is related to older age, complications, and chronic care living; individuals living in more rural areas are twice as likely to visit the ED as those living in cities | Munce et al, ¹⁷ 2009 | 12 | 559 |
| <ul style="list-style-type: none"> Outreach in the form of home visits from a multidisciplinary team from a rehabilitation centre led to fewer readmissions and improved rehabilitation outcomes | Prabhaka and Thakker, ²⁷ 2004 | 8 | 546 |
| <ul style="list-style-type: none"> A multidisciplinary Health Maintenance Education Program improves patient satisfaction with primary care and increases knowledge of respiratory complications, autonomic hyperreflexia, spasticity, aging, and community resources | Beck and Scroggins, ²⁹ 2001 | 6 | 19 |
| <ul style="list-style-type: none"> A specialized nurse-led community clinic provided up-to-date and readily applicable knowledge about bowel and bladder issues and skin breakdown, and was preferred over a medical clinic | Williams, ²⁶ 2005 | 4 | 31 |
| There is level 5 evidence that ... | | | |
| <ul style="list-style-type: none"> Half of those with a perceived need for physical rehabilitation receive it; significant predicting factors of access to health services include health plan type, health condition, health status, severity of condition, income level, and age | Beatty et al, ²⁸ 2003 | 14 | 800 |
| <ul style="list-style-type: none"> 52% of contact with GPs was for secondary complications; 34% of secondary complications are believed to be preventable; 72% of patients report an unmet need for health care, particularly rehabilitation services | Van Loo et al, ¹⁸ 2010 | 12 | 453 |
| <ul style="list-style-type: none"> Individuals with chronic SCI would like more information regarding aging with SCI and SCI research, and SCI educational information; ethnic minorities have the greatest unmet needs for information | Gontkovsky et al, ²² 2007 | 12 | 82 |
| <ul style="list-style-type: none"> 40% of physiatrists are willing to provide primary care to those with disabilities; 38% feel prepared by residency training to do so | Francisco et al, ³⁵ 1995 | 11 | 104 |
| <ul style="list-style-type: none"> Physiatrists consider bone health after SCI to be an important issue and favour pharmacologic treatment over rehabilitation | Ashe et al, ¹⁶ 2009 | 11 | 22 |
| <ul style="list-style-type: none"> There is considerable duplication between primary care and psychiatry; there is high satisfaction with primary care and psychiatry; needs for lifestyle and emotional issues often go unmet; there are differences in service use between those in Canada, the United States, and the United Kingdom, but no difference in access to and satisfaction with the services | Donnelly et al, ²¹ 2007 | 10 | 373 |
| <ul style="list-style-type: none"> 90% of individuals with SCI would like to receive written information about their conditions following medical checkups | Vaidyanathan et al, ³⁰ 2001 | 10 | 128 |
| <ul style="list-style-type: none"> 80% of issues raised by patients with SCI in primary care are related to disability; health promotion and counseling needs are typically unmet | Warms, ³⁶ 1987 | 9 | 59 |
| <ul style="list-style-type: none"> Barriers to specialized multidisciplinary outreach services are limited local expert knowledge, lack of funding, and service fragmentation | Cox et al, ³¹ 2001 | 9 | 54 |
| <ul style="list-style-type: none"> Most medical residents are not comfortable treating a women with tetraplegia who has recently become pregnant | Oshima et al, ³² 1998 | 9 | 44 |
| <ul style="list-style-type: none"> Patients receiving transitional, home-based rehabilitation as an outreach program from a rehabilitation centre experienced benefits in coordination and education of local providers, as well as family, community, and specialist involvement | Booth and Kendall, ²⁰ 2007 | 9 | 40 |
| <ul style="list-style-type: none"> Half of SCI outpatients consider psychiatry to be their primary care; 90% have little difficulty receiving medical care in the community | Bockeneck, ³³ 1997 | 8 | 144 |
| <ul style="list-style-type: none"> 75% of people with SCI have multiple clinical problems; patients made an average of 4 GP visits and received an average 4.5 home visits a year | Glickman et al, ³⁴ 1996 | 6 | 139 |

ED—emergency department, SCI—spinal cord injury.

*Levels of evidence according to Sackett et al, 2000.³⁸ Level 2 evidence includes quasi-experimental studies such as prospective studies and non-randomized comparison group and observational studies; level 3 evidence includes pre-experimental studies such as uncontrolled studies and historical and retrospective reviews; level 4 evidence includes observational studies including posttest-only designs, case series, and secondary analyses of administrative data; level 5 evidence includes surveys, case reports, and single-subject studies.

[†]Methodologic rigour score, evaluated on a scale from 1 to 20, with higher scores corresponding to higher levels of methodologic rigour; Downs and Black, 1998.³⁷

annual comprehensive preventive health evaluation.²³ Van Loo and colleagues¹⁸ found that 23% of visits to family physicians in their sample were to obtain annual follow-up. However, they reported that 72% of their sample had unmet needs, particularly related to rehabilitation consultation, telephone consultations, and home visits. Beatty and colleagues²⁸ found that unmet needs were greatest among those with the poorest health and lowest incomes.

Health issues of key importance in primary care for SCI

Fifty-eight percent of contacts with family physicians were related to secondary complications of SCI.¹⁸ Eighty percent of the issues raised in the typical family medicine encounter are related to disability.³⁶ The most consistently mentioned issues were bowel and bladder problems and pain.^{21,23,26,34,36} Also of concern are adaptive equipment,²³ prescription medications,²⁸ bone density,¹⁶ dermatologic issues,¹⁸ and spasticity.³⁴ Van Loo et al¹⁸ demonstrated that 34% of all secondary complications were preventable.

Unfortunately, there are a number of issues for which unmet needs have been observed in primary care specifically: psychological health, sexual and reproductive health, lifestyle, and community functioning.^{21,25,32,36} Unmet needs for information were also identified, especially regarding aging and current research.^{22,30}

DISCUSSION

This review found 21 articles that offer evidence regarding primary care for people with SCI. Most (19) were observational studies and surveys, with only 2 offering level 2 or 3 evidence. Typically, scoping reviews do not emphasize levels of evidence, but rather focus on the lessons that can be learned from interpretation of the collected literature.¹⁵ This review is specifically designed to offer family physicians an overview of the published literature on the care of patients with SCI in primary care.

There were 5 studies showing that multidisciplinary outreach programs working out of primary care settings can have promising health and service utilization effects for patients with SCI.^{20,26,27,29,31} Outreach programs included home visits, nurse-led clinics, multidisciplinary education, and transitional rehabilitation. By contrast, institutional outreach from rehabilitation to primary care was shown by Bloemen-Vrencken and colleagues¹⁹ to be unsuccessful in reducing selected secondary complications.

There is evidence for the importance of an annual comprehensive health examination.^{18,23} Several authors

also provided evidence for regular follow-up by specialized teams of medical and other multidisciplinary providers.^{21,31,33}

The research shows a high level of consistency in identifying the most common issues raised by people with SCI in primary care. Most of these issues are related to disability^{18,36}—specifically, secondary complications such as bowel and bladder issues and pain. However, there is also evidence that many general health issues require attention in this population, such as bone density,¹⁶ depression,²⁵ and sexual and reproductive health.³²

Patients with SCI are a small proportion of the typical family medicine case load. According to Wallace and Seidman³⁹ and Rosen,⁴⁰ 5% to 6% of the patients (ie, those with complex chronic conditions) consume about a third of a practice's resources, and require the services of a multidisciplinary team. Disabled patients can be high users of primary care and bring with them multiple needs and expectations.⁴¹ Despite the best of intentions, these needs might not all be met in the standard 10- to 20-minute family physician interaction.

There is evidence from 6 studies for unmet health needs among individuals living with SCI in the community.^{17,18,21,22,28,35} Despite high use of primary care and health services in general,^{17,21,34} information needs appear to be particularly poorly met.^{22,30} For patients who routinely attend appointments with 5 or 6 issues, of which only 3 can be raised, it is not surprising that unmet needs persist, regardless of the quality of care that is delivered. These unmet needs are most likely a product of the complexity of lifelong SCI and the ongoing need for creative, vigilant, responsive primary care.

The answer to this dilemma is not to simply ask more of family physicians. A number of articles have appeared in this journal recently to assist family physicians with better serving people with disabilities, including practice guidelines,^{42,43} educational recommendations,⁴⁴ and research articles.⁴⁵ Family physicians are used to focusing on disability, according to Jørgensen⁴⁶; however, they might not be familiar with the many challenges and manifestations that accompany disability. Bloemen-Vrencken and colleagues⁴⁷ and McColl and colleagues⁴⁸ provide review articles on models of primary care for people with disabilities. In their systematic review, Bloemen-Vrencken and colleagues⁴⁷ found that models such as teleconsultation, outpatient clinics, case management, and home visiting produced positive results in terms of secondary complications, service utilization, and well-being. McColl and colleagues⁴⁸ also reviewed a number of promising models, such as shared care, case management, self-management, and community-based rehabilitation.

Conclusion

Historically, many patients with SCI have used specialists (particularly physiatrists) to provide their primary care.⁴⁹⁻⁵² While this approach ensures a high degree of expertise in SCI, there are a number of arguments against it—not least among these is the clear preference by physiatrists to resist responsibility for primary care.³⁵

The literature is unequivocal that a robust system of primary care is the best assurance of good health outcomes for the population and of reasonable health service use.⁵³ The primary care system is best positioned to provide high-quality, holistic care for all, including people with SCI. Although the evidence is not strong, there appears to be sufficient consensus to advance several recommendations. We suggest that optimal primary care for patients with SCI might include the following:

- routine annual comprehensive health evaluation;
- multidisciplinary follow-up to address issues that accompany long-term disability;
- accessible premises that permit full examination of presenting health complaints;
- access to disability-specific expertise in the form of specialists, regarding common secondary complications such as pain and bowel and bladder complications; and
- awareness of areas in which there are often unmet needs, such as psychological concerns, sexual and reproductive health, and lifestyle issues.

Further research is needed to evaluate the validity of these recommendations.

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Contributors

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Competing interests

None declared

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