

Chapter VIII

Messengers and Methods of Disseminating Health Information among Individuals with Spinal Cord Injury: A Scoping Review

¹Guy Faulkner, ¹Paul Gorczynski, ¹Kelly Arbour, ²Lori Letts,
³Dalton Wolfe and ⁴Kathleen A. Martin Ginis*

¹Faculty of Physical Education & Health, University of Toronto, Canada

²School of Rehabilitation Science, McMaster University, Canada

³Department of Physical Medicine and Rehabilitation,
University of Western Ontario, Canada

⁴Department of Kinesiology, McMaster University, Canada

Abstract

People with spinal cord injuries (SCI) are at elevated risk for a variety of secondary health complications and chronic diseases such as diabetes and cardiovascular disease. In order to develop effective health promotion interventions, researchers and practitioners can draw upon a knowledge mobilization (KM) perspective that emphasizes the initial need to identify credible *messengers* and effective *methods* for conveying health messages. Adopting the methodological framework proposed by Arksey and O'Malley (2005), we conducted a scoping review to identify preferred delivery methods and messengers for health and physical activity information for individuals with SCI. The review consisted of a systematic search for information using existing databases of the published and grey literature, consulting collaborating partners from the SCI community for relevant documents and information, and sending out requests on a range of relevant

* University of Toronto, Faculty of Physical Education and Health, Toronto, ON, M5S 2W6, Canada. Phone: (416) 9467949 Email: guy.faulkner@utoronto.ca. This scoping review was funded by a Social Sciences and Humanities Research Council of Canada (SSHRC) Community-University Research Alliance grant.

listservs. Overall, the scoping review found little explicit reference to KM theories in the existing literature and little systematic examination of the efficacy and effectiveness of different methods and messengers. While the results of the review will inform the development of physical activity interventions tailored to this population, the results also suggest some significant gaps in the knowledge base concerning how best to disseminate health information to people with SCI.

Introduction

Spinal cord injury (SCI) affects over 50,000 Canadians (Canadian Paraplegic Association [CPA], 2000) with approximately 1,100 new injuries occurring each year (Rick Hansen Man in Motion Foundation, 2009). Recent medical innovations have led to tremendous increases in the life expectancy of people who experience an SCI. Depending on their injury level and completeness, people with SCI can expect to live almost as long as those without (Yeo, Walsh, Rutkowski, Soden, Craven, & Middleton, 1998). Accordingly, the focus in SCI medicine has shifted from acute life support to the management of health issues associated with long-term survival. In fact, the biggest health concerns faced by people with chronic SCI are impairments *secondary* to their injury (rather than the injury *per se*) and chronic diseases including obesity, coronary heart disease (CHD) and diabetes.

The Health of People with SCI

People with SCI are highly susceptible to a variety of secondary complications. The most prevalent physical impairments include urinary tract infections (UTIs), pressure sores, and musculoskeletal problems such as joint overuse, fractures and chronic pain (CPA, 2000; Guest, Klose, Needham-Shropshire & Jacobs, 1997; Jones, Goulding & Gerrard, 1998; Kocina, 1997). Psychological disorders, such as depression, stress and anxiety are also far more prevalent in the SCI population than the general population (Fuhrer, Rintala, Hart, Clearman, & Young, 1993; Kennedy & Rogers, 2000). Furthermore, from a functional/mobility perspective, given the sedentary lifestyle that usually follows an SCI, people with SCI typically experience declines in physical capacity (i.e., muscular strength and aerobic endurance) over and above those imposed by the SCI *per se* (Heath & Fentem, 1997). For example, only 25% of healthy young persons with paraplegia, and even fewer with quadriplegia, are believed to have the minimum level of physical fitness needed to perform the activities of daily living (ADLs) necessary to maintain functional independence (Noreau & Shephard, 1993; Noreau, Shephard, Simard, Pare, & Pomerleau, 1993).

With regard to chronic disease, diseases associated with obesity, such as diabetes mellitus, and CHD, are the greatest chronic health threats to people with SCI (Kocina, 1997). In fact, the SCI population is at an even greater risk for these diseases than the general population. People with SCI have less total lean body mass, less regional lean body mass and more fat than people who are able-bodied (e.g., Spungen et al., 2003) due to the characteristic muscle atrophy and physical inactivity associated with SCI (Kocina, 1997). In addition to being indicators of obesity, these characteristics are also related to insulin resistance and a

reduction in the body's capacity to use carbohydrates as an energy source (Aksnes, Hjeltnes, Wahlstrom, Katz, Zierath & Wallberg-Henriksson, 1996). Consequently, people with SCI may be up to 4 times at greater risk for developing non-insulin dependent diabetes mellitus (Type II diabetes) than the able-bodied population (Bauman & Spungen, 1994). Indeed, 22% of paraplegics have Type II diabetes (Imai, Kadowaki, Aizawa, & Fukutomi, 1994), as compared with 4.5% of the general Canadian population (Statistics Canada, 2002). People with SCI are also at greater risk for CHD due to lipid abnormalities. Accordingly, sedentary men and women with SCI are estimated to be at a 60% to 90% greater risk of heart attack than matched controls (Brenes, Dearwater, Shapera, Laporte & Collins, 1986).

The Cost of Compromised Health

Given the health issues described above, it should not be surprising that people with SCI report a poorer quality of life (QoL) than the general population (Dijkers, 1997; Post, van Dijk, van Asbeck & Schrijvers, 1998; Siosteen, Lundqvist, Blomstrand, Sullivan & Sullivan, 1990; Westgren & Levi, 1998). In addition to the personal costs of impaired health comes a staggering cost of living. Lifetime medical costs for just one person with a SCI can be as high as \$20 million (Rick Hansen Man in Motion Foundation, 2009). Along with the financial burden of an SCI come personal and social burdens. Costs associated with lost independence, increased family and caregiver load, and reduced vocational and social participation are inestimable, and contribute to a poorer QoL in people with SCI than those without (Dijkers, 1997; Kannisto, Merikanto, Alaranta, Hokkanen, & Sintonen, 1998; Post et al., 1998). However, through health promotion and prevention efforts, these costs can be reduced.

Reducing the Burden

Under the traditional system of health care in Canada, most resources are spent on diagnosing and treating disease, and few are directed toward disease prevention and health promotion. The disparity between treatment and prevention/promotion efforts is even greater for people with disabilities, for whom health promotion agendas are virtually nonexistent (Patrick, 1997). For instance, numerous public health efforts have focused on the primary prevention of SCI (e.g., campaigns to promote seatbelt and bicycle helmet use), but there have been minimal efforts to promote the health of people who already have a SCI. For instance, physical activity programs and information on how activity can promote health are the two services most desired but least available to people with SCI (e.g., Boyd & Bardak, 2004; Ipsos Reid, 2004; Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004). Yet with increasing awareness that people with disabilities are (a) susceptible to chronic conditions to the same or an even greater degree than the general population and (b) at risk for developing multiple secondary impairments (e.g., pressure sores, UTIs)(Marge, 1988), researchers and practitioners have called for an increased emphasis on the prevention of chronic disease and secondary impairments (Rimmer, 1999). In developing effective disease prevention and

health promotion interventions, it is critical to identify how they should best be delivered to specific populations.

Health Information and Knowledge Mobilization

A major barrier that prevents individuals with SCI from living a more healthful and active lifestyle is a lack of information (Block, Skeels, Keys, & Rimmer, 2005; Chase, 2004; Chase & Lanig, 1997). Some individuals with SCI may have a difficult time obtaining information that pertains to their condition and general health and well-being. Individuals with SCI need information about new technologies, diagnostic tests, and treatments; various general health needs; and how to improve their QoL (Brillhart, 2007). Information about physical activity for people with SCI is difficult to obtain (Block et al., 2005; Burkell, Wolfe, Potter, & Jutai, 2006; Chase, 2004; Chase & Lanig, 1997). Not knowing how or where to be active are two major information barriers that prevent individuals with SCI from being physically active (Block et al., 2005; Chase, 2004; Scelza, Kalpakjian, Zemper & Tate, 2005). These information barriers are deeply rooted in a knowledge mobilization (KM) network that may be failing to deliver necessary information to individuals with chronic health conditions and various health needs (Burkell Chase, 2004; Grol, 2001). KM is an active process that attempts to deliver knowledge obtained through systematic research and experience to individuals that need it most (Lavis, Robertson, Woodside, McLeod, & Abelson, 2003). By allowing individuals in the community to access and utilize information that was previously only known to researchers, better decisions can be made by the general public about health and any necessary treatments.

Researchers in the field of KM have identified five essential, evidence-based principles of disseminating information to communities (Lavis et al., 2003). These principles include: 1) understanding the target audience; 2) tailoring messages and practices to suit the audience; 3) using credible messengers; 4) using effective methods of communication; and 5) measuring the effectiveness of KM.

Stages 1 and 2: Understanding the target audience and tailored messaging

Researchers and practitioners emphasize that it is vital to understand the audience and their needs for information before any KM strategy is constructed. Currently, it is known that individuals with SCI are physically inactive and experience various comorbidities. More health related information is required by individuals in this population to facilitate health and treatment related decision-making. The diverse needs of the SCI community make the task of delivering information especially challenging. KM must be constructed in such a manner to address different injuries, stages of injury recovery, and health concerns (Burkell et al., 2006). Additionally, issues of age, gender, ethnicity, education, marital status and socio-economic status need to be carefully considered.

Stage 3: Credible messengers

Research has shown that the credibility of the messenger, whether it be a single individual or a group of individuals, has a tremendous positive effect on the transfer of information (Shonkoff, 2000). Traditionally, credible messengers included individuals in academia, research, or medicine (Lavis et al., 2003). However, given the number of different health professionals with whom individuals with SCI come in contact and the low availability of specialists (Burkell et al., 2006), the range of potential messengers available for delivering information to this population is more diverse. In order to deliver health and physical activity-related information to individuals with SCI, it is necessary to not only identify credible messengers for this population, but also those that are most preferred.

Stage 4: Methods of information delivery

Methods of communicating information to individuals can be either passive or interactive (Lavis et al., 2003). Examples of passive processes of delivering information include journals, manuals, newsletters, and DVDs. In order to access information in these sources, individuals must first be aware that these sources exist and then be motivated enough to actively seek out required information. Alternatively, interactive methods of delivering information include face-to-face contact, discussion groups, patient education programs, and Internet chat programs. Research has shown that the more interactive the method of communication, the more likely the message will be received by the intended audience (Oxman, Thomson, Davis, Hayes, 1995). Given the wide variety of available methods to deliver information to individuals with SCI, it must be determined which are most effective and preferred by individuals in this population.

Stage 5: Evaluating the effectiveness of KM

Existing KM strategies need to be examined for their effectiveness given that individuals in the SCI community are currently not active, experience various life-shortening comorbidities, and have a difficult time obtaining information. Various researchers suggest a community-based approach to constructing and evaluating KM interventions and strategies (Altman, 1995; Huberman, 1994). Such an approach provides an opportunity for researchers to learn more about their intended audience and what information is needed most. Additionally, this model allows individuals that are part of the target audience to be active members in the research process. Their participation will shape what information will be transmitted and who will deliver it. By working collaboratively with the SCI community, researchers would find out what information should be delivered, who should deliver this information, how this information should be delivered, and whether this information is being delivered effectively. Only by evaluating the effectiveness of the KM process will researchers and community members know whether information is being received by the target audience, how this information is being used, and how the KM process can be improved.

Scoping Review

Based on the five stages of the KM model described by Lavis and colleagues (2003) and the tenets of community based research, a scoping review was undertaken to explore models and frameworks of KM and common and preferred messengers and methods of information delivery pertaining to general health and physical activity used within the SCI community. The specific purpose of this scoping review was to develop an inventory of dominant models of KM, KM messengers, and KM methods that help deliver SCI-specific information to individuals living with SCI in Ontario, Canada, and around the world. Barriers and facilitators to receiving information from various messengers and methods were also addressed. This scoping review is part of a larger community-based project designed to increase physical activity participation in the SCI community by developing, mobilizing, and evaluating evidence-based interventions that inform, teach, and enable individuals in the SCI community to become and stay physically active. Our ongoing, collaborative endeavour is bringing together university-based researchers, knowledge mobilization specialists, support networks, service groups and community members focused on advancing physical activity, knowledge and participation among Canadians living with SCI. This chapter represents an important first step towards developing a KM framework for subsequent intervention development and delivery. Further information about the project can be found at <http://www.sciactioncanada.ca>.

Methods

Systematic reviews of randomized controlled trials (RCTs) and meta-analytic evidence often provide the basis of most knowledge syntheses, and traditional systematic reviews often end at this point. However, publication bias is an acknowledged problem of meta-analyses (Thornton & Lee, 2000). A large number of research projects never reach publication in an indexed journal, and those that do tend to involve statistically significant, positive findings (Sterne, Egger, & Davey Smith, 2001). Consequently, potentially important information is not easily accessible to researchers who restrict their literature searches to recognised databases such as MEDLINE or EMBASE and who limit their analyses to include only RCTs or meta-analyses. In addition to publication bias, there are many limitations to conducting RCTs for many interventions, especially in such relatively small yet heterogeneous populations such as SCI (Martin Ginis & Hicks, 2005). Therefore, the current body of evidence for many interventions, including those involving physical activity, for individuals with SCI is often comprised of descriptive studies involving case series, case control or pre-post study designs (see Arbour and Martin Ginis, this volume). Additionally, lessons that may be learnt from different, but related fields of research, may be ignored completely.

Accordingly, research questions pertaining to KM models, messengers, and methods were addressed through a scoping review. Scoping reviews are distinct from systematic reviews in that a) they often address broad topics where a variety of study designs and secondary topics may be relevant, b) they are less likely to formally assess the quality of included studies or use study quality criteria to guide the synthesis of data, and c) they are

used to identify parameters around a body of literature, and to identify gaps in the existing body of research. In contrast, systematic reviews tend to be characterized by more focused questions, incorporate criteria for assessing quality of included studies, and are often not attempted in areas with limited published information. A methodological framework proposed by Arksey and O'Malley (2005) was adopted for conducting this scoping review. This included obtaining information by searching existing databases, collaborating with community partners and other national and provincial organizations, asking key national and international informants (as identified by our partners) for relevant documents and information, and sending out requests on a range of relevant listservs. Throughout this process, a member of the SCI community also collaborated with the research team in evaluating the evidence and providing input to consensus building around the research questions.

This scoping review involved the following five stages:

1. Identifying the research questions
2. Identifying relevant studies
3. Study Selection
4. Charting the Data
5. Collating, Summarizing and Reporting the Results

Below, each stage will be described in greater detail.

Stage One: Identifying the Research Questions

Initially, a broad approach was taken to identify research questions. These questions were designed to examine a wide variety of subject areas when a search of the literature was performed. Questions were primarily designed to explore KM models, messengers, and methods with respect to general health and physical activity. The primary research questions for this scoping review included the following:

1. What are the preferred delivery methods for health information for individuals with SCI?
 - a. In general?
 - b. In relation to physical activity?
2. Who are the preferred health information messengers for individuals with SCI?
 - a. In general?
 - b. In relation to physical activity?

Barriers and facilitators to delivering information for each messenger and method were examined as well. Sub-questions were also created to address other issues concerning KM. These questions pertained to underlying models and theoretical constructs of KM in the SCI community. A general exploration was conducted to determine which models were most effective at disseminating information.

Stage Two: Identifying Relevant Studies

In total, three sources of information were included in this scoping review. Information was based on published research, grey literature, and contextual literature.

Published Literature

The published literature searched in this scoping review covered a range of study types, including RCTs, quasi-experimental and pre-experimental studies, cohort studies, cross-sectional studies, and qualitative research. No time limits restricted the search and studies were identified up to the time the scoping review was initiated (December 2007). Studies that focused on individuals with SCI and were written in English were included in the results. Due to resource restrictions, studies were excluded if they were written in a language other than English. Databases were searched using the following terms: Spinal AND Information AND Source; Spinal AND Information AND Needs; Spinal AND Knowledge AND Mobilization; Spinal AND Knowledge AND Message; Spinal AND Dissemination; Spinal AND Help AND Management; and Spinal AND Health Promotion. Databases that were searched for relevant studies included: Cochrane Database of Systematic Reviews; Database of Abstracts of Reviews of Effectiveness; Cochrane Central Register of Controlled Trials; Medline; EMBASE; Psychinfo; Health Management Information Consortium; Applied Social Science Index and Abstracts; ETD Digital Library – Network Digital Library of Theses and Dissertations; Proquest Digital Dissertations; SPORTDiscus; Cumulative Index of Nursing and Allied Health Literature (CINAHL); AMED – Allied and Complementary Medicine; PEDRO (Physiotherapy Evidence Database); OTSeeker.com; and Educational Resources Information Center (ERIC). The reference lists of relevant included studies were also inspected for additional studies.

Grey Literature

A substantive component of the literature search was the identification of ‘grey’ literature including evaluation reports, policy documents, evidence-based guidelines, contract research reports, program descriptions, government publications as well as documents published by non-government organizations, and material presented at conferences. Several steps were taken to identify ‘grey’ literature. First ‘grey’ literature databases were searched using the same criteria listed in the Published Literature section above. Databases included: Canadian Research Index (microlog); Dissertation abstracts (Proquest); Grey Literature report (<http://www.nyam.org/library/greyreport.shtml>); PapersFirst (OCLC); Proceedings First (OCLC); and World Cat (OCLC). Second, information in the form of unpublished evaluation reports, program descriptions, guidelines, or internal publications was sought from community partners at a joint annual meeting. The following partners were asked for information: Canadian Paraplegic Association (CPA); Active Living Alliance for Canadians with a Disability (ALACD); Canadian Paralympic Committee (CPC); Rick Hansen Man in

Motion Foundation (RHMIMF); Ontario Neurotrauma Foundation (ONF); Ontario Rehabilitation Research Advisory Network (ORRAN); and the Ontario Ministry of Health Promotion (OMHP). Additionally, community partners provided relevant listservs and websites that could be searched to help identify pertinent materials. Lastly, leading websites were searched that targeted the SCI community locally, provincially, nationally, and internationally.

Contextual Literature

Reviews, meta-analyses, and book chapters published since the year 2000 were reviewed for information about theoretical frameworks and KM messengers and methods used by other communities that live with disabilities. This literature synthesized and integrated evidence related to the primary and secondary research questions. The objective of this 'review of reviews' was to synthesize the results of the best available literature to develop recommendations for promoting physical activity within the SCI community in terms of KM messengers and methods. Two databases were used in this search: MEDLINE and PsycINFO. Both databases were searched using the following terms: physical activity AND health promotion AND disability; and physical activity AND disability. All reviews were assessed for relevance using the following criteria: 1) it was a review article or chapter; 2) the topic was relevant to the research questions; and 3) a search strategy and inclusion/exclusion criteria were described in the review article or chapter.

Stage three: Study selection

Unlike systematic reviews, the development of explicit exclusion and inclusion criteria for individual articles was determined post hoc after the research team gained familiarity with the literature that the search strategy uncovered. For this review, a study team meeting was conducted in order to develop exclusion and inclusion criteria after the literature had been searched. The study team decided to include literature that pertained to SCI or other mobility disabilities, KM theories and models, and KM messengers and methods. Overall, 81 articles were selected for review. These articles were then supplemented by a further 17 articles or reports suggested from secondary sources for a total of 98 articles comprising the scoping review.

Stage four: Charting the data

In order to chart the data, pertinent information was recorded about each of the selected studies (i.e., authors, study location, year of publication, description of what study involved) along with some analytical details including key findings, and agreement and disagreement with other studies. Some studies were charted in duplicate to assess the reproducibility of the data extraction process, and to facilitate discussions in the study team regarding the process of data extraction. Retrieved studies were charted in EXCEL by two reviewers and were used as a basis for the following stage. This file is available on request from the first author.

Stage five: Collating, summarizing and reporting the results

For the current review, studies were thematically organized and the relevant information from each study was retrieved that addressed our research questions. Information was extracted and compiled in a narrative format with no attempt to present judgments on the weight or quality of evidence in certain areas. Additionally, with ongoing interaction and exchange with community partners, community members helped the study team in identifying any topics that needed further consideration and providing interpretive insights on the evidence retrieved. Five community members participated in community consultations over the course of this scoping review. Community members were contacted by either telephone or email and were broadly asked the main questions of the scoping review. Contributing members included individuals with and without SCI, all of whom were employed by organizations that support SCI initiatives. A synthesis of the findings drawn from the full range of evidence sources is now presented.

Results

Messengers of Health and Physical Activity Information

A variety of health professionals, educators, friends and family members were identified as messengers of general health and physical activity-related information. Messengers of health and physical activity included trained educators, clinical nurse educators, health care specialists, physicians, physical therapists, occupational therapists, massage therapists, chiropractors, coaches, teammates, family members, peers, peers with SCI, mentors, and other health care providers. Some studies specifically differentiated information about general *physical activity* from information about *sport* participation. Studies that discussed *sport* participation reported that information was most beneficial when it came from coaches, peers with SCI, friends, and family (Chase & Lanig, 1997; Slater & Meade, 2004; Wahman, Biguet, & Levi, 2006; Wu & Williams, 2001). One study that examined youth living with SCI reported that family, friends, and peers with SCI are the preferred messengers of health and physical activity information (Njoki, Frantz, & Mpofu, 2007). Other studies that examined communication methods and messengers best suited to individuals with SCI reported that specialists (physicians who specialize in SCI) were the most preferred messengers to deliver health information (Burkell et al., 2006; Gontkovsky, Russum, & Stokic, 2007; Potter, Wolfe, Burkell, & Hayes, 2004). Although many different messengers were identified, the effectiveness of different messengers was not assessed. Several studies did recommend that different messengers be used at different times of the rehabilitation process (Burkell et al., 2006; Leibowitz, 2006; Rick Hansen Man in Motion Foundation, 2004a; Rick Hansen Man in Motion Foundation, 2004b).

The 'review of reviews' identified many of the same messengers of health and physical activity information found in published and grey literature. Individuals that delivered physical activity information to individuals with disabilities included: athletic trainers (Block et al., 2005; Kennedy, Taylor, & Hindson, 2006; Maher, Kinne, & Patrick, 1997; van der

Ploeg et al., 2007); exercise physiologists (Froehlich-Grobe & White, 2004); nurses (Warms, Belza, Whitney, Mitchell, & Stiens, 2004); peers with a disability (Block et al., 2005; Hughes, Nosek, Howland, Groff, & Dolan Mullen, 2003; Robinson-Whelen, Hughes, Taylor, Colvard, Mastel-Smith, Nosek, 2006; Zemper et al., 2003); physical therapists (Block et al., 2005); and researchers (O'Connor, 2000).

The community members involved in the community consultations mentioned various messengers to deliver health and physical activity information and confirmed the messengers identified in the review of the published, grey, and greater disability literature. All members mentioned primary health care professionals and peers with SCI as the primary messengers of health related information. Most community members noted that specialists and peers with SCI were the most preferred messengers. One member mentioned that individuals with SCI have a great deal of 'faith' in expert health care professionals and their opinions, but these professionals are difficult to access. Other messengers of health and physical activity information mentioned by the community members included rehabilitation staff (e.g., occupational therapists (OT), physical therapists (PT), nurses, rehabilitation counselors, wheelchair support association employees), family, friends, and other health care professionals (e.g., general physicians, recreation therapists). With respect to obtaining information specifically about competitive sports, community members mentioned that the most preferred messengers included coaches, health care therapists (i.e., rehabilitation counselors, OT, PT, MDs), friends, peers with SCI, and family members. Lastly, one member suggested that lawyers could play a bigger role in disseminating physical activity information by helping recently injured individuals plan for the high costs of activities, memberships, and equipment and help plan financial settlements accordingly.

Delivery of Health and Physical Activity Information

Several studies found in the published and grey literature identified various forms of passive and interactive forms of delivering information to individuals with SCI. The most common form of delivering health and physical activity related information was through patient education programs that promoted self-care and in a few cases, exercise (Chase & Lanig, 1997; Chase, 2004; Froehlich-Grobe & White, 2004; Kennedy et al., 2006; Kinne, 1999; Laskin, James, & Cantwell, 1997; Maher et al., 1999; Norris, Vise, Warton, Noble, & Atrickland, 1982; Rimmer et al., 2004; Warmes et al., 2004). These programs usually consisted of multi-method approaches that offered face-to-face contact, lectures, discussion groups, demonstration sessions, manuals, videotapes, and DVDs (Block et al., 2005; Brady Kruger, Helmick, Callahan, & Boutaugh, 2003; Hughes et al., 2003; Kennedy et al., 2006; Kinne, 1999; Laskin et al., 1997; Latimer, Martin Ginis, & Arbour, 2006; Maher et al., 1999; Marks, Allegrante, & Lorig, 2005a, Marks, Allegrante, & Lorig, 2005b, May, Day, & Warren, 2006a, May, Day, & Warren, 2006b, Norris et al., 1982; Robinson-Whelen et al., 2006; Rosman, Ohry, & Rozin, 1982; Sable & Bocarro, 2004; Scotzin, 1990; Stuijbergen, Becker, Blozis, Timmerman, & Kullberg, 2003; Zemper et al., 2003; Zip, 2005). A few studies reported on the usage of computer programs, CD-ROMs, Internet, online databases (e.g., MEDLINE), email, and chat programs and websites (Brillhart, 2007; Burkell et al.,

2006; Chase, 2004; Drainoni et al., 2004; Edwards, Krassioukov, & Fehlings, 2002; Gontkovsky et al., 2007; Kosma, Cardinal, & Mccubbin, 2005; Latimer et al., 2006; Manns & May, 2007; Picket Hauber et al., 2002; Potter et al., 2004; Rowland, White, & Wyatt, 2006; van Biervliet, 1999). Although some studies identified computers and the Internet as preferred methods of delivering information (Burkell et al., 2006; Drainoni et al., 2004; Picket Hauber et al., 2002; Kosma et al., 2005; Nguyen et al., 2004; Picket Hauber et al., 2002; van Biervliet, 1999), issues of computer and Internet accessibility are frequently mentioned as barriers to information for individuals with SCI (Drainoni et al., 2004; Goodman, Jette, Houlihan, & Williams, 2008; Picket Hauber et al., 2002; van Biervliet, 1999). In addition to computers and the Internet, sources of mass media were also used to deliver information about health and physical activity. These methods included disability sport magazines, sport science journals, newsletters, books, television, videotapes, and DVDs (Chase, 2004; Froehlich-Grobe & White, 2004; Nguyen, Carrieri-Kohlman, Rankin, Slaughter, & Stulbarg, 2004; Potter et al., 2004; Slater & Meade, 2004; Stuijbergen et al., 2003; van der Ploeg et al., 2007; Warms et al., 2004; Wu & Williams, 2001; Zemper et al., 2003). Although many different forms of delivering information were identified in the published and grey literature, no studies directly compared one method against another. Studies indicated that various methods be used at different stages of the rehabilitation process and that methods be tailored to meet the specific learning needs of the service users (Burkell et al., 2006; Kinne, 1999; Kosma et al., 2005; van der Ploeg et al., 2007; Warms et al., 2004). For instance, methods should be designed for both inpatient and home-based service users and take into consideration the information needs of the individual at a particular stage of injury. Individuals with a recent SCI who are in the rehabilitation phase may require more individual support, opportunities to participate in group or demonstration sessions; whereas individuals who have lived with SCI for some time may prefer information to be delivered through an accessible channel like the internet.

The information obtained through the 'review of reviews' established similar findings as the published and grey literature. Findings showed that physical activity information was primarily delivered to individuals with disabilities by group or one-on-one sessions and done either in the community or in the home. Methods of information delivery included: education seminars and workshops (Block et al., 2005; Froehlich-Globe & White, 2004; Hughes et al., 2003; Kennedy et al., 2006; Maher et al., 1999; Robinson-Whelen et al., 2006; Zemper et al., 2003); the Internet (Kosma et al., 2005); the telephone (Froehlich-Globe & White, 2004; Latimer et al., 2006; van der Ploeg et al., 2007; Zemper et al., 2003); and written materials (Latimer et al., 2006; Warms et al., 2004; Zemper et al., 2003).

When community members were asked about available and preferred methods to deliver health information to individuals with SCI, various methods were recommended. Four members recommended that information be tailored and easily accessible through the Internet and email. Additionally, all members recommended as much direct face-to-face contact with health care professionals and peers. One member mentioned that individuals with SCI are most likely to be open to all sources of information regarding general self-care and health while participating in rehabilitation shortly after their injury. Two members mentioned that individuals should not be directed to resources, but rather given them. For instance, individuals with SCI should be given a binder with information about self-care and not given

a website or mailing address where they can indirectly obtain information. Additional methods of information dissemination available included “disability focused” publications (e.g., CPA Ontario/CPA National, Rick Hansen, Canadian & American Spinal Research Organization (CSRO), Abilities Magazine, Why Not Magazine, Active Living Magazine, Sport and Wheelchair, Abilities, Active Living, and Sports and Spokes), phone hotlines, videos, DVDs, take-home resources, and memory sticks with reading materials. With respect to physical activity and sport related information, community members recommended similar methods to delivering general health information.

Barriers and Facilitators to KM

A number of barriers and facilitators that hampered or enhanced information transmission were discovered in the published and grey literature. With reference to patient education programs, some barriers included a lack of adult learning theory used to structure interventions, and a lack of supplementary information, family involvement, and interesting class formats (May et al., 2006a; May et al., 2006b; Potter et al., 2004). With specific reference to general women’s health information, one study reported that women with SCI felt overwhelmed with the process of being seen as ill and disabled and did not want to continually visit physicians or other healthcare professionals (Persaud, 2000). Women in this study also reported that physicians were uncomfortable with their disability and being asked to perform certain screening procedures. Several studies reported that individuals with SCI felt that physicians and health care professionals showed little enthusiasm providing information and lacked knowledge in areas like aging, health promotion, pain management, physical activity, and sexual health (Persaud, 2000; Pickett Hauber, Vesmarovich, & Darfur, 2002; Rainville, Pransky, Indahl, & Mayer, 2005; Rimmer, Braddock, & Pitetti, 1996; Rinatala et al., 2004; Scelza et al., 2005; Sims, Kerse, Naccarella, & Long, 2000; Warren, 1985; Zip, 2005). Regarding multimedia methods of information dissemination, potential barriers included a lack of money to purchase technology, access to computers and the Internet, and literacy levels (Nguyen et al., 2004; Pickett Hauber et al., 2002; Potter et al., 2004; van Biervliet, 1999). Other barriers included a lack of awareness of programs or information sources, accessibility to programs, finances, confidence, facilities, transportation, and support groups (Block et al., 2005; Burkell et al., 2006; Chase, 2004; Drainoni et al., 2004; Froehlich-Grobe & White, 2004; Kennedy et al., 2006; Kosma et al., 2005; Njoki et al., 2007; Rimmer et al., 2004; Rowland et al., 2006; Sable & Bocarro, 2004; Scelza et al., 2005; Slater & Meade, 2004; Stuijbergen et al., 2003; Wahman et al., 2006).

Facilitators that enhanced information dissemination included mutual, family, and peer support (Harrison, 2006; Hughes et al., 2003; Kahn et al., 2002; Kinne, 1999; Maher et al., 1999; Marks et al., 2005a, Marks et al., 2005b; Njoki et al., 2007; Potter et al., 2004; Robinson–Whelen et al., 2006; Sherman, DeVinney, & Sperling, 2004; Slater & Meade, 2004; van der Ploeg et al., 2007; Wahman et al., 2006; Wu & Williams, 2001; Zemper et al., 2003) and matching appropriate information needs of individuals with their progress through a rehabilitation framework (May et al., 2006a; May et al., 2006b; Potter et al., 2004). Future interventions should also consider issues such as gender, age, and ethnicity to improve

knowledge mobilization (Drainoni et al., 2004; Gontkovsky et al., 2007; Kinne, 1999; Kleinginna Gallaher & Hough, 2001).

The 'review of reviews' addressed various barriers and facilitators to health and physical activity information. The most frequently cited barriers dealt with transportation and accessibility. Several possible solutions and facilitators were identified to overcome various barriers to obtaining physical activity information. Facilitators included accessible transportation (Block et al., 2005); accessible locations (Hughes et al., 2003; Maher et al., 1999); appropriate facilities (Kennedy et al., 2006); choice of location (i.e., home, community centre) (Froehlich-Globe & White, 2004); equipment availability (Block et al., 2005); gender-specific interventions (Hughes et al., 2003); and low program fees (Block et al., 2005; Maher et al., 1999).

Community members involved in the community consultations mentioned a variety of barriers and few facilitators to successfully disseminating information to individuals with SCI. All members noted that accessibility and transportation were major issues because it prevented individuals from attending healthcare appointments, seminars, and workshops. Members also mentioned that getting around was more difficult during the winter because of severe weather conditions. As a result, electronic information available over the Internet would be most ideal. Although the Internet was seen as a convenient method of disseminating information, three members expressed caution over the quality of the content and the credibility of individuals writing and posting such information. These members mentioned that although there is a great deal of information currently available online, it is very easy to get distracted and not find what was searched initially.

Community members also addressed other barriers to information about health and physical activity. Three members mentioned that physicians can act as barriers to obtaining health and physical activity information. These members noted that physicians are not always available and that scheduling appointments can take a long time. One member also mentioned a 'grey hair belief' that referred to 'older physicians' not promoting physical activity because they did not believe in its value and potential benefit. This member noted that younger physicians were more likely to understand the value and benefits of physical activity and therefore promote it.

One member mentioned some individuals with SCI lack the motivation necessary to seek community programs, available resources, and information pertaining to physical activity and general health. This individual recommended that people with SCI and low motivation be assigned a rehabilitation counselor so they have access to one-on-one follow up counseling, resources, and training.

Parents of youth with SCI were also seen as barriers to information dissemination and physical activity participation. One member mentioned that certain parents were overly concerned about safety and wanted to 'bubble wrap' their children to prevent them from getting hurt. Ultimately, these parents influenced what information their children received about physical activity and which activities they participated in.

Another barrier that prevents individuals with SCI from being active is the usage of the word 'sport' in health promotion campaigns. One member mentioned that the word 'sport' implies a highly organized and competitive environment saturated with rules and regulations and expectations that may intimidate certain individuals. This member recommended using

the words 'physical activity' to promote a comfortable and noncompetitive way to being active.

Lastly, another barrier that was brought up by three members was the lack of financial resources and the high cost of new equipment and programs. Members felt that high costs and low incomes or government subsidies or settlement packages prevented them from being full participants in obtaining health and physical activity information and being active.

With respect to identifying facilitators to improve information dissemination to individuals with SCI, members only had a few suggestions. Members suggested that successful programs should be gender and age specific and incorporate friends, family, and peers with SCI. Additionally, members noted that belonging to certain organizations that mailed/mailed newsletters and information and planned social and informational gatherings on a regular basis as being helpful.

Models or Theories of Knowledge Mobilization

Very few studies in the published and grey literature mentioned theories of KM to deliver health information or structure interventions. A few studies that discussed multimedia and computer based technology referred to an Interactive Health Communication Model where the consumer and clinician communicated through the Internet or telephone (Nguyen et al., 2004; Pickett Hauber et al., 2002; van Biervliet, 1999; Warms et al., 2004). One study discussed Orem's Self-Deficit Theory used to foster education and skill development with the intention to promote client self-care through the Internet (Brillhart, 2007). Some studies also mentioned a patient education framework but failed to discuss any models or theories that structured their interventions (Anderle, 1995; May et al., 2006a, May et al., 2006b; Norris et al., 1982). The Transtheoretical Model was also used to structure stage specific interventions (Kinne, 1999; Kosma et al., 2005; van der Ploeg et al., 2007; Warms et al., 2004). Lastly, a few studies also mentioned the importance of self-efficacy to promote self-care and health management (Brady et al., 2003; Marks et al., 2005a, Marks et al., 2005b; Stuijbergen et al., 2003; Zemper et al., 2003).

The 'review of reviews' identified multiple underlying theories and approaches used to structure and ultimately deliver health promotion. Theories and approaches included: behavioural management (Block et al., 2005; Hughes et al., 2003; van der Ploeg et al., 2007; Warms et al., 2004); empowerment models (Robinson-Whelen et al., 2006); social support (Frehlich-Globe & White, 2004; Hughes et al., 2003; Kennedy et al., 2006; Zemper et al., 2003); self-efficacy (Hughes et al., 2003; Zemper et al., 2003); Social Learning Theory (Robinson-Whelen et al., 2006); Theory of Planned Behaviour (Latimer et al., 2006); Transtheoretical Model (Kosma et al., 2005; van der Ploeg et al., 2007; Warms et al., 2004).

Two members involved in the community consultations were aware of models used to develop strategies for getting information to the SCI community. They mentioned a peer support program named 'Change of Minds, Change of Lives' offered through the Canadian Paralympic Committee. The program was described as a sport specific strategy that aimed to have healthcare professionals promote sport and physical activities to individuals with SCI.

The program was described as a 'rehabilitation through sport' model. No other models or theories were mentioned by any of the community members.

Discussion

Research that is exploring the field of KM in the SCI community is particularly new, with most research being conducted within the last five years. This scoping review identified various common and preferred messengers, methods, and models of delivering information about general health and physical activity to individuals with SCI. Current published and grey literature along with experiences shared by community partners and members helped suggest that although there may be an extensive list of messengers and methods, not all messengers and methods need to be utilized at once. The results of this scoping review illustrate that individuals with SCI may have specific preferences as to who should deliver information pertaining to general health and physical activity and how this information should be delivered.

Individuals with SCI generally prefer health information to be delivered by specialists or highly trained healthcare professionals and peers with SCI (Burkell et al., 2006; Kennedy et al., 2006; Rick Hansen Man in Motion Foundation, 2004a; Rick Hansen Man in Motion Foundation, 2004b). Although specialists are perceived to be one of the most credible messengers, people with SCI recognize that these individuals are extremely difficult to schedule appointments with. Even though people in the SCI community have a great deal of faith in the information that is obtained from specialists and highly trained health care professionals, individuals with SCI recognize valuable information can be obtained from peers that live with SCI. When discussing messengers and physical activity, it is necessary to distinguish between information needs for habitual or recreational physical activity and sport participation (Slater & Meade, 2004; Wahman et al., 2006; Wu & Williams, 2001). Several researchers and community partners and members have reported that messengers who are familiar with SCI and the particular sport of interest should deliver information that pertains to sport participation. Individuals with SCI perceive coaches, peers with SCI, family and friends to be the most credible messengers when it comes to delivering sports related information. With respect to information pertaining to physical activity, people with SCI value the opinions of healthcare professionals, peers with SCI, friends and family. Although individuals with SCI face many barriers to accessing health and physical activity related information and services, two common information barriers are most often reported (Block, Skeels, Keys, & Rimmer, 2004; Chase, 2004; Scelza et al., 2005). These information barriers include (i) not knowing how to exercise or be physically active, and (ii) where to exercise or be physically active. Although numerous methods to deliver information have been identified by individuals with SCI, mediated forms of communication, such as the Internet or telephone services, are seen as the most preferable methods (Burkell et al., 2006; Kennedy et al., 2006; Rick Hansen Man in Motion Foundation, 2004a; Rick Hansen Man in Motion Foundation, 2004b). These methods of communication allow individuals with SCI to obtain information from credible messengers who provide specialist research information that fosters the ability to make more informed healthcare and quality of life related decisions.

Throughout this scoping review very few theories, models, or frameworks to deliver information were identified. Some studies reported the usage of behavioural theories to address and improve individualistic and social aspects such as intentions, self-efficacy, motivation, and social support. These studies primarily relied on the Transtheoretical model (Kinne, 1999; Kosma et al., 2005), Social Cognitive Theory (Brady, Kruger, Helmick, Callahan, & Boutaugh, 2003; Hughes et al., 2003; Marks et al., 2005a; Marks et al., 2005b), Social Learning Theory (Robinson-Whelen et al., 2006), and the Theories of Reasoned Action and Planned Behaviour (Sable & Bocarro, 2004). Other models and frameworks were utilized as well to deliver information. These models were based on an Interactive Health Communication strategy and utilized intermediary sources or mediated forms of communication, such as the Internet or the telephone to connect individuals with SCI to necessary expert health and physical activity related information (Burkell et al., 2006).

Although many different models, messengers, and methods of delivering information were identified in this scoping review, and certain messengers and methods were identified as most preferable, no models, messengers, or methods were compared or evaluated directly for their effectiveness. With no research comparing the effectiveness of different models, messengers, and methods for delivering information to individuals with SCI, progress will be compromised with respect to improving current KM practices. Given that individuals with SCI have a difficult time accessing information for various reasons, direct comparisons of methods, messengers, and methods are vital to improving access to and utilization of health related and physical activity information. With improved access to information, individuals with SCI will be able to make more informed decisions about their conditions, healthcare options, and available treatments ultimately leading to a better quality of life.

Implications for Healthcare Professionals

Although many different messengers were identified, individuals with SCI have specific preferences as to who should be delivering information about physical activity. Physicians and other healthcare professionals need to recognize their status as credible messengers of health related information and must make efforts to educate their clients about the importance of physical activity. These individuals need to emphasize how people with SCI should be physically active in a safe manner, what equipment is necessary to be physically active, and where individuals can partake in physical activity. Most importantly, healthcare professionals need to encourage and motivate individuals with SCI to be physically active in order to preserve and improve their health and well-being. In addition to providing encouraging and motivating healthcare, specialists and various healthcare professionals should become familiar with mediated forms of communication, such as telephone counseling and Internet chat and email programs. Interactive Health Communication models allow individuals with SCI to receive the specialized care and information they seek, but in a manner that circumvents most major accessibility issues such as scheduling challenges, inaccessible facilities, transportation difficulties, and cost issues. Healthcare professionals must also realize the importance, value, and necessity of the friends and family members of individuals with SCI to help deliver information. These individuals can provide a great deal of advice

and information to individuals with SCI and can provide the necessary social support that is often needed to initiate and maintain physical activity regimens. Greater inclusiveness of peers, friends, and family members throughout the rehabilitation process must be embraced and encouraged by healthcare professionals.

Implications for Policy

People living with SCI suffer from severe and chronic health complications that require a great deal of care and attention (e.g., bladder infections, chronic pain, diabetes). In addition to increased health care, individuals with SCI require information to sustain and improve their health and well-being. Current KM models do not provide sufficient information about general health conditions and treatments and physical activity to individuals with SCI. Policy experts need to recognize the importance of aligning KM models, messengers, and methods with individual needs. Careful attention needs to be paid to the amount and kinds of information that is provided to individuals at different stages of injury as well considering gender, age, ethnicity, socio-economic status, marital status, and education levels. Issues of accessibility such as overcoming cost challenges, inaccessible facilities, transportation difficulties, and access to different technologies and technological services need to be also taken into account. Given that many individuals with SCI enjoy receiving information through mediated sources such as the telephone or the Internet, making sure that individuals with SCI have access to computers and Internet services should be a primary goal for policy makers. Not only would Internet service provide a great deal of information to people living with SCI that could be obtained through websites, but it would also connect these individuals with credible messengers that could supplement information and healthcare needs through Interactive Health Communication models. Most importantly, current and future policy strategies should concentrate on supplying specialist and expert information to individuals with SCI as easily as possible. These strategies would help improve an individual's ability to make more informed healthcare decisions and also enable the individual to participate in physical activity programs in his or her community.

Future Research

Although this scoping review recognized a wide variety of messengers, methods, and models, it also identified several gaps in the KM literature that pertains to SCI. There are multiple areas of research in the field of KM that need to be examined more closely in order to structure more effective physical activity interventions and facilitate greater access to information and opportunities to be physically active. Future research should investigate the following areas: 1) what methods and messengers are preferred at what particular treatment times by individuals with SCI?; 2) what is the efficacy and effectiveness of different methods and messengers at different treatment phases?; and 3) how do issues relating to gender, age, socioeconomic status, marital status and ethnicity influence method and messenger preferences?

Many different messengers, methods, and models were identified in this scoping review, yet no studies explored the efficacy or effectiveness of any particular messengers, methods, or models. Although there was expressed desirability to receive information from credible messengers, such as SCI specialists, and to utilize mediated forms of communication like the Internet (Burkell et al., 2006), the effectiveness of such messengers and methods was not measured. Future research not only needs to address which preferable messengers, methods, and models are most effective, but also examine when during the rehabilitation process such messengers, methods, and models should be used. One study conducted by Leibowitz (2005) that explored women's experiences and concerns with inpatient sexual rehabilitation in an SCI facility found that interventions that were stage-specific and provided not only different types of information but also different amounts of information at various stages of the recovery process were more beneficial. Such considerations need to be made when designing interventions to increase physical activity for individuals with SCI.

Many of the studies found through this scoping review identified barriers to information and ultimately physical activity; however, few suggested any solutions. Barriers often included a lack of access to information, poor transportation services, few accessible facilities, high costs of programs and equipment, no access to computer or Internet services, healthcare professionals' poor knowledge of SCI and the role of physical activity in the lives of individuals with SCI, complications, and low availability of healthcare professionals and SCI specialists. The solutions to help overcome these barriers mainly concentrated on changing individual-level attributes such as attitudes and beliefs, self-efficacy, social support, or becoming more informed about various social services and healthcare provisions. Future research should also consider broader policy and environmental interventions aimed at creating or enhancing access to places for physical activity including the means to get to those places (see Kahn et al., 2002).

Several studies in this scoping review noted that issues relating to gender, age, ethnicity, and socioeconomic status play a role in determining the success of a physical activity intervention. Studies that examined the difficulties women with SCI experience accessing information and services reported that gender-specific interventions would improve women's access to various programs, treatments, and healthcare services, and ultimately, their quality of life (Hugues, Nosek, Howland, Groff, & Dolan Mullen, 2003; Persaud, 2000; Robinson-Whelen et al., 2006). Although the majority of individuals living with an SCI are men (i.e., 80%), it is necessary to address the concerns felt by women with SCI. Future studies should consider examining the effectiveness of interventions that incorporate gender sensitive features.

When structuring an intervention to increase physical activity for individuals with SCI, aspects of age need to be carefully considered (Gontkovsky et al., 2007). Given that the age individuals incur an SCI injury is increasing (Pickett, Campos-Benitez, Keller, & Duggal, 2006), researchers will need to address both aspects of age and injury severity when designing and implementing interventions to increase physical activity. These interventions will not only have to address the large number of individuals that experience an SCI before the age of 30 years, but also the growing number of individuals that are above the age of 50 years (Pickett et al., 2006).

Several studies in this scoping review addressed the impact of ethnicity on access to healthcare and treatment-related information (Drainoni et al., 2004; Gontkovsky et al., 2007; Kleinginna Gallaher & Hough, 2001). In a cross-sectional survey of 103 individuals living with SCI, Gontkovsky and colleagues (2007) identified that ethnicity predicted perceived information needs, with Blacks and American Indians reporting a significantly higher need for health-related information. Another cross-sectional study found similar results (Drainoni et al., 2004), with individuals that are from ethnic minorities experiencing greater difficulty accessing health-related information on the Internet and as a result, a lower quality of life. Given that individuals of various ethnicities require different kinds and amounts of information, researchers must take into consideration these variables and structure interventions that allow greater access to information.

Aspects of socio-economic status need to also be considered when structuring physical activity interventions for people living with SCI. Research has shown that socio-economic status determines the kind of equipment individuals with SCI will utilize, the resources individuals will have in order to participate in physical activity programs, the modes of transport individuals will use, and the kinds of information to which individuals have access (Drainoni et al., 2004; Gontkovsky et al., 2007; Kahn et al., 2002; Kleinginna Gallaher & Hough, 2001). Given these issues are related to socio-economic status, policy makers and researchers will need to carefully address these aspects when structuring interventions to increase information to physical activity for individuals with SCI.

Future research should explore the effectiveness of programs that take into consideration aspects of gender, age, ethnicity, and socio-economic status. By taking an inclusive community-based approach to future intervention studies, researchers and community members will be able to acknowledge and examine a wide variety of variables and implement strategies that are culturally sensitive and satisfy the unique needs of different communities.

Conclusion

Overall, the scoping review found little explicit reference to KM theories in the existing literature and little systematic examination of the efficacy and effectiveness of different methods and messengers. As a consequence, the review did not identify any one method or messenger for health promotion as being more or less efficacious than other options. Rather, there was evidence to suggest individuals with SCI had different health information needs at different times. For practice and intervention, this confirms a need to consider multiple methods with multiple messengers to promote opportunities for client choice and in order to match preferences with provision. This review did not suggest the need for an extensive range of methods and/or messengers but that there was interest and acceptability for some specific options. In particular, mediated communication – through Internet with telephone or email support - appeared acceptable and feasible. Computer and Internet use is high in this population and the Internet holds considerable potential as a long-term knowledge exchange modality after SCI (Goodman et al., 2008). There was some indication of need and preference for initial face-to-face interaction (e.g., safety concerns) with SCI specialists, and ongoing contact with a focus on self-management (problem solving) approaches. There was consistent

interest in peer mentoring in some form as a context for sharing information about health promotion. While the results of the review will inform the development of physical activity interventions tailored to this population, the results also suggest some significant gaps in the knowledge base concerning how best to disseminate health information to people with SCI. Addressing the identified research gaps will be essential for developing an evidence-based KM framework for health promotion in the SCI community.

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