
MOVE AGAIN PROGRAM: LITERATURE SEARCH

PART 2

**“BARRIERS TO EXERCISE FOR PEOPLE WITH SPINAL
CORD INJURIES”**

SELECTED SUMMARY POINTS

- The evidence about ‘barriers and supports to exercise for people with SCI’ is very limited. However, a larger body of research is available when the topic is broadened from SCI to ‘people with disabilities’ and from ‘exercise’ to ‘physical activity’.
- The evidence comes from diverse methodological approaches (with significant related limitations) and is reported in literature spanning many fields of study including rehabilitation, therapy, psychology, physical activity/exercise, nursing, health promotion, social work, social policy and others.
- Despite the variety of models of ‘barriers and supports’ proposed, there is high level of consistency in the findings, thus constituting a ‘pool’ of reported influences on exercise behaviour.
- People with SCI experience multiple and interacting constraints and supports to physical activity in addition to those faced by the general population, and these occur in many domains including functional, psychological, architectural, social, and political.
- The relative importance of specific barriers and supports, and the relationship between them is highly variable - within and between individuals, disability types/severity, occasions, and social and physical contexts.
- In both the general and SCI populations, there are low levels of uptake and adherence to exercise programs, and cessation of an exercise program results in loss of any benefits gained.
- Adherence to exercise programs may be particularly challenging for people with SCI and pain may be a significant barrier.
- Amongst people with SCI, those with greater limitations will in most cases encounter greater barriers and require more supports in order to exercise.
- In people with tetraplegia and paraplegia it is difficult to achieve and maintain a level of exercise that is adequate for ‘fitness’.
- Lifestyle physical activity (living e.g. lifting groceries, wheeling up ramps instead of taking lifts etc) is feasible and acceptable and may be an effective approach to increasing physical activity in people with SCI.
- For people with SCI, ‘constraints and supports’ form only one part of a complex pattern of behavioural influences on participation in physical activity – some of which are unique to the SCI population.
- The relationships between the identified barriers/supports, and the mechanisms by which they influence behaviour, are not well understood for people with SCI and are a current topic of investigation.
- In recent years, researchers have increasingly recognised the need to complement descriptive utilitarian studies with a more theoretical approach that offers explanatory and predictive potential for use in attempts to modify exercise behaviour by people with SCI.

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1. INTRODUCTION AND PURPOSE

This report is one of four foundation documents produced as a result of the Move Again Program's (MAP's) background research phase. The other documents are:

- Move Again Program: Literature Search: Part I: Exercise and Spinal Cord Injury
- Move Again Program: Information Scan
- Move Again Program: Survey Development

The purpose of these documents is to provide background information for MAP investigators and associates who collectively represent a wide range of academic and clinical backgrounds and whose experience with the SCI population is highly variable – from full time clinical involvement to very little direct contact.

The topic for this review is:

“Barriers and supports to participation in structured physical exercise by people with SCI”.

It refers to both physical activity and to structured physical exercise undertaken by people with SCI at any time following the acute and sub-acute rehabilitation phase, and in any context e.g. at home, outdoors, at fitness/recreation facilities including those in a hospital, clinic, centre, university, or within the community.

This topic was identified by MAP investigators as important because in general, people with SCI participate in less regular and vigorous physical activity and it is believed that this is largely due to various ‘barriers’ that increase the time and energy requirements and, in some cases, injury risk for potential participants (eg (Scelza, Kalpakjian et al. 2005).

In addition to identified barriers and supports, there are many other significant factors known to be associated with the level and type of participation in physical activity in both the general population and SCI subgroup e.g. age, gender, level of education, socioeconomic group, geographic location and others (eg (Sallis, Hovell et al. 1992). These broader factors have not been discussed in this review. However, several specific considerations relevant to physical activity in the SCI population are briefly considered i.e. degree of impairment, age at time of SCI event, and time since SCI event.

2. DEFINITIONS AND METHOD

2.1 DEFINITIONS

Several conceptual and definitional issues are noted below for clarification and consistency.

Physical activity

All leisure and non-leisure body movements resulting in an increased energy output from the resting condition (Warburton, Sproule et al. 2006).

Exercise

Structured and repetitive physical activity designed to maintain or improve physical fitness (Warburton, Sproule et al. 2006).

Participation

This notion extends from ‘engagement’ through to ‘adherence’ and ‘maintenance’.

Activity

The literature on barriers and supports refers to a range of **activities** with a physical activity component and with varying levels of formality and structure e.g. ‘leisure activities’, ‘physical activity’, ‘exercise’, ‘fitness activity’, ‘physical therapy’, ‘physical rehabilitation’ etc. Few refer specifically to ‘structured physical exercise’. The contexts of activity also vary and in addition to rehabilitation settings, include out-patient facilities, exercise at home, special facilities, and community facilities.

Barriers

This concept is considered in terms of ‘constraints’. (Jackson 1988), defined ‘constraints’ as factors that “inhibit people’s ability to participate in leisure activities, to spend time doing so, to take advantage of leisure services, or to achieve a desired level of satisfaction” (p. 203). In practice, this inhibition ranges from very minimal, to complete prevention – in which case it becomes a ‘barrier’. The early conceptual and remedial focus on various physical and architectural constraints was mostly targeted at highly or totally inaccessible situations, and this further promoted the notion and terminology of ‘barrier’. Research literature predominantly refers to self-reported perceived ‘barriers’ and in many cases there is little indication of the level of ‘constraint’ actually experienced.

Support, facilitator, enabler

These terms are closely related and are used almost interchangeably in the literature.

In this report we have used the terms ‘**constraints**’ and ‘**supports**’ except where directly reporting findings, in which case, the terminology used is that of the authors.

2.2 METHOD

The search method included various online searches and gathering of information from reports identified during the environmental scan and previous projects known to the consultants.

The topic is one that has been approached from a variety of disciplines but without sustained research and reporting in periodicals or other publications.

Most literature was identified using generic search engines (Google and Google Scholar), and following up various databases that had been used in Part I Literature Review and that had revealed any discussion of the 'barriers' topic. The publications identified include academic papers in reputable journals, reports of commissioned research/evaluation, and fact sheets and other documents from various disability organisations.

Search terms employed in various combinations were:

SCI, spinal cord injury, physical disability, mobility

barrier* constraint* impediment* concerns

facilitat* support* enable*

participat* engage* adher* maintenance

structured physical exercis* activit* therapy fitness sport recreation program* rehabilitat*

The initial search results were used to identify related publications, references from key articles, and selected authors. These were then followed up in subsequent searches.

3. SEARCH RESULTS

The literature specifically reporting relevant and robust research on barriers and supports to structured exercise by people with SCI proved to be very scant. We therefore **expanded the search** to the broader disability and physical activity fields in order to further explore relevant aspects of the topic. The identified studies were reported in a wide range of fields including rehabilitation, therapy, psychology, physical activity/exercise, nursing, health promotion, social work, social policy and others.

A wide range of **methodological approaches and limitations** was apparent within the identified studies. Many of these have been discussed in the Move Again Program: Literature Search Part I (2008), and further described in detail by (Martin Ginis and Hicks 2005). The majority of identified studies were atheoretical and exploratory, mostly qualitative and descriptive with much of the reported information coming from anecdotal evidence. Where randomised control trials were located, the numbers and variability of subjects did not enable satisfactory representativeness or equivalence of groups. Studies in which quantitative elements had been introduced often used 'one off' instruments, modified instruments, or general instruments that had not been validated on the 'disability' population or the SCI population. Within the broader research on exercise and 'disability', in most cases only a few SCI subjects had been included and their results were often indistinguishable from those of the broader group.

Despite the range of methodological approaches and limitations, the findings from a wide range of studies indicate a high level of **consistency in the identified barriers and supports**. This is, to some extent, encouraging in terms of providing a ‘pool’ of commonly expressed influences on exercise behaviour.

The literature on constraints and supports to exercise has been conducted not only across a range of disability groups and physical activity contexts, but also for **a variety of purposes** e.g. to guide policy, to inform service planning, to explore the utility of various theories of behaviour, to develop strategies for behavioural and structural change etc. The studies range from specific research on exercise in SCI populations to examination of general leisure activities undertaken by ‘people with disabilities’. The lack of uniformity and coherence of the results reported in this review reflects these differences. The **results have been presented in detail** to illustrate this diversity of approach and outcome. For discussion purposes selected findings have been loosely grouped into

- ‘models’ of activity constraints for people with disabilities
- application of general models of behaviour to exercise/physical activity in the SCI population
- constraints and supports identified in applied work (usually atheoretical).

4. SPECIFIC ‘MODELS’ OF ACTIVITY CONSTRAINTS FOR PEOPLE WITH DISABILITIES

A dominant general model discussed within the ‘constraints to exercise’ topic is a **‘personal-environment interaction’** model. The WHO approach, for example, provides a conceptual model for study of factors that influence activities and participation in a wide range of life situations (including physical activity/exercise) by people with disabilities. They aggregated these factors into two main categories: **personal factors** e.g. gender, age, race, lifestyle, upbringing and social background, and; **environmental factors** i.e. those related to physical, social, and attitudinal environments e.g. products and technology, community attitudes, health and social supports (WHO 2001). Others have applied this general model to the broader study of barriers to health and wellness in people with disabilities, and have stressed the need to go beyond focussing on the individual’s motivations and impairments and to include consideration of social, cultural and architectural environments (Putnam, Geenan et al. 2003).

A recent Canadian approach also supports two broad categories of barriers to physical activity for people with disabilities (Smith, Austin et al. 2005).

- **Intrinsic barriers** - resulting from an individual’s physical, emotional, and cognitive limitations; residing within the individual; temporal or permanent; may arise or be related to causes such as parental overprotection, inadequate educational opportunities, and segregation from peers e.g.
 - Lack of knowledge
 - Social ineffectiveness
 - Health problems
 - Physical and psychological dependency
 - Skill/challenge gaps
- **Environmental barriers** - often physical e.g. architectural, trees, mountains; or can be imposed by society or economic conditions e.g.
 - Attitudinal barriers
 - Architectural barriers

- Ecological barriers
- Transportation barriers
- Rules and regulations barriers
- Barriers of omission

The authors note that although intrinsic barriers can often be overcome through personal action, environmental barriers are 'imposed' on individuals many of whom consequently feel helpless to overcome them. This notion is also embodied in the **Social Theory of Disability** (eg (Oliver 1995).

In an ethnographic study of barriers and enablers to participation in physical activity (8 adults with paraplegia) (Levins, Redenbach et al. 2004) also proposed two key themes:

- **individual influences** - defined as a period of loss of "able identity" and subsequent redefinition of self in which participation in physical activity may be a vehicle or an outcome
- **societal influences** - included environmental and attitudinal barriers.

Similarly, an investigation of **women with disabilities** in community recreation settings reported that "the emotional toll" of being in negative public situations and the experience of "pity" affected their attitudes toward leisure, and that although physical and financial restraints were often part of the equation, social and psychological comforts were reported as the key to participation (Bendini and Henderson 1994). These results are consistent with the **social model** in that they remove the focus from the person's impairments, and rather, highlight the environmental, attitudinal, and social barriers that result in disablement e.g. the availability of accessible facilities, programs, and equipment stems from the attitudes and priorities of those in that society. Individual factors, such as attitudes and intentions, are seen to be inseparable from the physical and social environment - internal struggles, physical barriers, and resources interact and intersect to create the larger picture. The authors further noted the frequent difficulty in distinguishing between 'individual' and 'societal' barriers - e.g. a person's geographic location affects not only the physical accessibility of local facilities, but also the availability of programs and equipment.

Other authors emphasise the relative importance of 'individual' factors. For example, (Kinne, Patrick et al. 1999) noted that while various theories might infer that external barriers (lack of access, transportation, funds, and social support) would be the most important factors, the only important predictors of exercise maintenance were, in fact, attitudinal factors (self-efficacy and motivation) of the individuals themselves. Concurring with (Levins, Redenbach et al. 2004), they also noted that there may be difficulties in distinguishing between these factors e.g. some people might refer to "being too tired" or "not being interested," while others would call the same issue "lack of money," recognizing that with more money, less energy would be spent in order to be able to participate, and that the 'saved' energy would make it possible to be less tired and more interested.

Several models include more than two categories of constraints in order to attempt to explain some of the complex interactions between person and environment. For example, (Crawford and Godbey 1987) proposed:

- Intrapersonal constraints which involve individual psychological states and attributes that interact with activity preferences rather than intervening between preferences and participation e.g. stress, fear of safety, anxiety, confidence, motivation, prior socialisation into specific leisure activities, perceived self-skill, and beliefs about the appropriateness and availability of various leisure activities. In addition, people with disabilities also include fatigue and pain, the disability itself, lack of knowledge about where to find a program, and limited access to knowledge about their capabilities for activity.
- Interpersonal constraints arising from interactions with others such as family, friends, co-workers; and including lack of social support/companionship for participation in physical activity.

- Structural constraints that are barriers arising from external conditions in the environment e.g. lack of time, money, transport, or accessibility issues, suitable equipment and access to knowledgeable staff.

These researchers later added a hierarchical approach to the key elements (Crawford, Jackson et al. 1991) whereby they suggested that an individual might experience constraints at any one or all three of the levels, and that the solution would be most important at the intrapersonal end of the continuum rather than at the structural end of the continuum. A later study reported that higher levels of intrapersonal constraints were associated with lower likelihood of participation in sports (Alexandris and Carroll 1997). These authors further suggested that if intrapersonal constraints can be overcome, individuals are likely to participate in sport activities even when interpersonal and structural constraints are present.

Based on the Australian experience, an alternative approach with a strong focus on service provision also proposed three broad categories of barriers to recreation for people with disabilities:

- Barriers found in the community e.g. attitudes, poor understanding, cost, transport, physical access – often brought about by ignorance, misconception stereotyping, and fear
- Barriers imposed by disability services e.g. misconceptions about recreation, lack of service linkages, lack of access to information/support
- Barriers for the individual e.g. lack of social skills, communication, motivation, low self-expectation, inappropriate behaviour, fear, lack of a friend or companionship. (Culyer 1997, cited in Edgecombe and Crilley, 2002)

This author further notes that while a recreation service provider has an obligation to facilitate participation by addressing attitudes and aspects of service accessibility, the responsibility for participation lies largely with the person with a disability who may or may not be adequately prepared and equipped to meet this challenge.

A cross-sectional survey study of barriers to exercise among 72 SCI individuals dwelling in Michigan USA reported three categories of most frequently cited concerns about barriers

- Intrapersonal or intrinsic (e.g., lack of motivation, lack of energy, lack of interest)
- Resources (e.g., cost of an exercise program, not knowing where to exercise), and
- Structural or architectural (e.g., accessibility of facilities and knowledgeable instructors) (Scelza, Kalpakjian et al. 2005).

In this study specific perceived barriers (expressed as ‘major concerns’) were identified as

- Poor accessibility
- Lack of privacy
- Fear of injury, and
- Public exposure of personal injuries.

Participants also noted that lack of experience (with SCI) of fitness centre staff was a problem when starting an exercise routine.

5. THE APPLICATION OF GENERAL MODELS OF BEHAVIOUR TO PHYSICAL ACTIVITY FOR PEOPLE WITH SCI

Several research groups have applied well-accepted general theories of behaviour to exercise behaviour in people with disabilities with a view to examining the explanatory and predictive power, and thus utility for development of physical activity strategies for this group.

One recent example specifically involving people with SCI, is that of a Canadian questionnaire-based study which applied the **Theory of Planned Behaviour** (Latimer, Martin Ginis et al. 2004). The results indicated that for those with paraplegia none of the key constructs predicted exercise intentions or behaviour, and that for those with tetraplegia only perceived behavioural control was of any predictive value. The authors concluded that, for the SCI population, this well accepted theory has limited utility. They also suggested that **Bandura's Social Cognitive Theory** may be more suited to exploring exercise in people with SCI. The conclusions of this study also suggest the need for caution in extrapolating to the SCI population the explanatory and predictive claims of theories that are based on general populations. In later SCI research, however, members of this research group addressed some of the limitations of the previous study and subsequently reported that their later findings did, in fact, support the tenets of **Theory of Planned Behaviour**. Moreover, they also suggest that given the many barriers to structured physical activity for people with SCI, greater emphasis should be placed on '**leisure time physical activity**' e.g. gardening, wheeling around the block to take the dog for a walk, rather than focussing only on structured physical exercise (Latimer and Ginis 2005).

In a further exploration of elements of the **Theory of Planned Behaviour**, these authors more closely examined implementation intentions in a randomised control trial with 54 SCI individuals (Latimer, Ginis et al. 2006). They evaluated the efficacy of an 8-week implementation intention intervention that involved 30 min of moderate to heavy intensity physical activity 3 times per week. Participants who formed implementation intentions were found to engage in more physical activity, have sustained motivation and greater confidence to schedule physical activity compared with participants in the control condition. The authors suggested the possibility of a role for implementation intentions in health promotion programs for people with spinal cord injury.

Others have applied the constructs and barriers suggested by the **Transtheoretical Model** of behaviour change to examining the stages of change for exercise behaviour among 322 adults with a wide range of physical disabilities (Cardinal, Kosma et al. 2004). The results indicated that barriers and the behavioural processes of change, self-efficacy, and decisional balance were very important to physical activity participation.

Within various psychological and social approaches, the notion of **self-efficacy** is now quite prominent in understanding and promoting exercise behaviour in the general population. Its application in SCI populations is currently an area of considerable activity by researchers and specific measurement instruments are under development (eg (Kroll, Kehn et al. 2007). Similarly the notion of **perceived behaviour control** has been identified as a predictor of exercise among people with tetraplegia (Latimer, Martin Ginis et al. 2004). These authors noted the need to identify and promote exercise that reduces the difficult-to-control barriers for this group.

These studies indicate that researchers have recognised the need to complement descriptive utilitarian studies with a more theoretical approach that offers explanatory and predictive potential

for use in attempts to modify exercise behaviour.

6. CONSTRAINTS AND SUPPORTS IDENTIFIED IN APPLIED PROJECTS

The following studies were predominantly applied or exploratory in nature rather than expressing or implying any theoretical approach. They were mostly focussed on program evaluation or development of policy and/or procedures.

6.1 STUDIES OF SCI

A 4-month evaluation of the effectiveness of a comprehensive and holistic wellness program for 30 men and 13 women with traumatic and non-traumatic SCI was conducted using a randomised clinical trial in the USA (Zemper, Tate et al. 2003). It adopted biometric tests (fasting blood draw for total cholesterol; arm ergometry testing for endurance; neurological examination, and Body Mass Index) and survey questionnaires (Wellness survey; Health Promoting Lifestyle Profile-II, Secondary Conditions Scale, Self-rated abilities for Health Practice Scale, Perceived Stress Scale, and the Physical Activities with Disability (PADS) Questionnaire. The intervention ("Well on Wheels!") consisted of six 4-hour workshop sessions at the University of Michigan hospital, and included the topics; lifestyle management, physical activity, nutrition, and preventing secondary conditions. It also included individual coaching sessions with each of the three module teachers and two follow-up phone calls by the project managers. The major concerns identified by the participants as barriers to physical fitness were

- lack of motivation (54%)
- cost of an exercise program (40%)
- not knowing where to exercise (36%)
- lack of interest (34%).

Over one half of participants stated that they felt a fitness centre would not be able to meet their needs as a person with SCI, and 34% cited accessibility and privacy concerns about exercising in such a facility.

Using a health promotion approach, another USA study examined the acceptability and feasibility of a lifestyle physical activity program for 16 non-exercising adult volunteers with SCI (Warmes, Belza et al. 2004). In a single group pre-post-test design, the administered program comprised educational materials, home visit by a nurse, construction of a personal plan to increase activity, and four follow-up phone calls. Participants rated program acceptability, stage of change, barriers to health-promoting activities, abilities for health practices, health, depression, and muscle strength. Physical activity was monitored using actigraphy and a self-report record. While some subjects noted a preference a structured exercise approach, most rated the program positively, with 87% progressing in stage of change and 60% increasing their physical activity. There were significant changes in motivational barriers, and improvements in exercise self-efficacy, self-rated health, and muscle strength.

Using focus groups, the following barriers to exercise were reported in a study of 10 Canadian 'exercisers' and 'non-exercisers' from the SCI community (Martin, Latimer et al. 2002):

- accessibility (including transport)
- pain

- psychological barriers e.g. depression, low confidence, worries about physical limitations and inability to match pre-injury activities
- time e.g. functional limitations mean that everything takes longer and there is less time available for exercise
- lack of information about available exercise opportunities, or benefits of exercise

These participants also highlighted aspects of the program that they found motivating and that facilitated their ability to overcome barriers:

- accessibility e.g. equipment, space, scheduling
- volunteers
- personal trainers
- social support from other participants

Barriers to home exercise programs (HEPS) for SCI patients were identified in an investigation of veterans receiving care at the SCI Center of the VA Palo Alto Health Care System (122), and; therapists (105) (Manring and Kiratli 2005). This investigation surveyed reported patterns of adherence, perceived barriers, expected outcomes, and views on strategies for improving success with HEPs. For SCI individuals the main reported **barriers** to HEP adherence were:

- motivation (38%)
- hard to fit into daily routine (33%)
- lack of energy (29%)
- “too lazy to exercise” (23%)
- lack of time (23%)
- lack of interest & doing own activity is enough (both 17%).

The participants also noted other issues that indicate ‘**supports**’ to their activity eg

- desire for increased family or friend involvement in their HEP in the form of a work-out partner (54%)
- wish for encouragement to participate (48%)
- belief that increased therapist contact would help to increase adherence to HEPs (reported by 45% of SCI participants and 57% of therapists).

Using a qualitative case study approach a Swedish study (Wahrman, Biguet et al. 2006) identified four factors that may promote participation in physical activity among people with spinal cord injuries. A qualitative multiple case study approach was used involving structured interviews with 16 people with SCI who been physically active post injury. Four main themes of **activity-promoting factors** were identified:

- using cognitive and behavioural strategies – finding a role model, creating routines, goal setting, acquiring new knowledge, recalling previous experience, exposure to and accepting assistance
- finding environmental solutions – increasing accessibility, social support, equipment and funding
- exploring motivation post injury – gaining and maintaining independence, experiencing health, improving physical appearance, becoming a role model, becoming competitive, establishing a self-image that is active, experiencing pleasure, becoming part of a social network and being needed
- capturing new frames of reference – learning to live with narrower physical margins, learning to read your body, acquisition of new physical strategies.

The authors concluded that the process towards a physically active life may be facilitated by utilising these factors and also the motivational power of role models.

In a study of exercise maintenance in seven Canadians with SCI who had recently completed a 9-month study of exercise training, adherence to twice weekly participation in supervised exercise at

a university centre had significantly decreased after 3 months. The authors noted that adherence may be particularly challenging for this group, and that pain may be a significant barrier (Ditor, Latimer et al. 2003).

Others report that the most common strategies for promoting adherence to recreation and exercise programs are: varying the activities and/or locations, and supportive social networks (Rimmer and Schiller 2006).

Overall, the body of reported robust research on influences on exercise behaviour specifically in the SCI population is not substantial. However, the current information about ‘constraints and supports’ to activity in this group is valuable for policy and evaluation purposes, and increasingly contributes to the development of research with a more theoretical approach, and ultimately, the articulation of a strong basis for change in exercise/physical activity behaviour.

6.2 STUDIES OF ‘PEOPLE WITH DISABILITIES’

The following Australian and international studies of constraints and supports to exercise were not specifically focussed on SCI but on a range of disabilities including those associated with SCI.

A South Australian study of 161 ‘people with disabilities’ (Edgecombe and Crilley, 2002) conducted focus groups and surveys to elicit ‘issues of importance’ when participating in community sport and recreation. The results, in order of reported importance, broadly suggest barriers and supports:

- Provision and promotion of accurate information to me about ‘disability friendly’ access, amenities, venues, services and programs
- Service providers knowing and understanding how they can overcome barriers to my participation (rated most highly by those with vision impairment or an injury)
- Access to programs/services within community groups for me (rated equally most highly by those with intellectual impairment – with transport)
- Knowing about the range of funding sources for programs and services (rated most highly by those with a ‘nervous system’ impairment)
- Availability of support services/personnel for me (rated most highly by those with musculoskeletal impairment)
- Access to equipment that assists my participation
- Availability of transport (rated equally most highly by those with intellectual impairment – with access to programs/services)
- Having access to frequent and regular updates on information and ideas from other South Australians with a disability
- Service providers having better details about me and others with a disability e.g. favourite sport, arts, other activity
- Knowing about the benefits of my participation in sport, arts and other recreation choices
- Successful athletes and artists with a disability as role models.

In WA, a recent environmental scan investigated many aspects of participation in community-based sport and recreation by people with disabilities (Lockwood and Lockwood 2007). A small sample of ‘non-participants’ (n=11) offered a range of reasons for non involvement represented by the following quotes:

- Accessibility - “have given up because there are just too many barriers” e.g. “Facilities not accessible or appropriate (e.g. no seats, no air conditioning)”, “use crutches and wheelchair...it just gets too hard

- Assistance from staff and others - I don't feel that the staff are interested in making an effort", "Tried joining a gym a few times but didn't go for long because couldn't operate the machines independently, staff were too busy to help – I wouldn't try again because I need more attention than others in the class and no gym has accommodated that" "Too difficult without a carer to dress and transfer me from car"
- Personal limitations and motivation – e.g. chronic fatigue, pain – "lost interest because I can't do what I used to enjoy", "no desire or energy to do so"
- Awareness of opportunities - "haven't played sport for many years and wouldn't know where to go and get involved"

In this scan the barriers reported by 'participants' (n=35) and representatives of disability service organizations included:

- Support unavailable/unaffordable – applies to both 1:1 instruction and to ongoing assistance.
- Cost of public facilities - e.g. "especially if a carer is also required...therefore I take part at my organization"
- Transport - e.g. "taxis won't go short distances", "bus routes not comprehensive", "main road crossings inaccessible"
- Inadequate knowledge and experience of staff (and volunteers, and coaches)
- Facility, venue, and program issues e.g. Lack of air conditioning, seating, shade, cool areas, programs not available after work and weekends, long distance from car park to pool e.g. "difficulty getting back to the car after exercising...too much of a challenge...I stopped attending", wet floors in change rooms, lack of privacy, no seating in change rooms, lack of continuous pathway, branches overhanging footpaths, etc
- Access to information about facilities and programs
- Community and participant attitudes – "do not want us to be there", "there is no place for me once it gets competitive – it's all about winning"
- Physical limitations – fatigue, pain etc.

In another West Australian example, the Town of Victoria Park surveyed its residents with a disability and their carers as part of the development of its Disability Access and Inclusion Plan (Fletcher 2005). People with a disability mostly reported

- information barriers e.g. information about activity opportunities
- physical barriers e.g. poor access to the facility, lack of accessible parking, and
- economic barriers.

Of respondent carers, 65% indicated 'Never participating in recreation, leisure or social activities' and identified the following barriers to doing so:

- Lack of information regarding activities
- Lack of free time
- Work commitments
- Issues relating to health, age and disability
- Lack of formal assistance
- Lack of energy
- Lack of transport
- Live out of the area
- Not enough variety to do things together
- Lack of choice options geared toward 'oldies'

In particular, the following were identified as preventing or restricting the carer from participating with the person they provide care for in recreation, leisure or social activities:

- Lack of information regarding activities
- Nothing interesting to me
- Lack of transport

- Age and disability
- Work commitments
- Lack of free time
- Lack of motivation
- Cost
- Lack of ACROD parking

Barriers to inclusion of people with disabilities in community sport and recreation have also been reported in other Australian studies e.g.

- Clients with disabilities perceived that staff of Western Australian recreation centres had little understanding of disability issues and were uncertain of what steps needed to be taken to ensure safety and access (Lockwood and Lockwood 1996)
- Participants with disabilities who attended Western Australian metropolitan recreation services noted limitations imposed by their disability, financial restrictions (usually associated with low disposable income), dependence on parents and friends to provide transport, lack of information about current and future programs, and the lack of suitable programs in the local area (Lockwood and Lockwood 1991)
- Interviews and focus groups with over 500 people with disabilities (including families and carers) living in Victoria identified barriers to physical activity including: negative attitudes in the Victorian community; insufficient support services; insufficient funding for the activity, transport, and/or equipment or materials; high cost, limited income; access issues e.g. steps, buses, light switches, disabled toilets, footpaths, kerbs, seating, and; lack of, or difficult to access, information (Johnson 2000)

In 1998 an Australia-wide information gathering exercise was undertaken to provide the Australian Sports Commission Participation Division with feedback to its National Programs and Indigenous Sport Units (Cormack 1999). A series of community discussions was conducted across Australia to gather information from physical activity delivery agencies in order to gain an understanding of their attitudes and support needs with relation to specific groups including people with a disability. Although the study casts a wider net than that required for this review, it's results may provide some additional insights into the **service provider perceptions about barriers and supports to participation** in a community activity setting (including for people with SCI). The overarching finding was that local service delivery groups felt under-prepared to include and cater for people with special needs. Their apprehensions were related to some of the following identified barriers to inclusion:

- Lack of volunteers with specialist training to support individual disabilities
- Not enough people with a common disability to make up a competition structure (e.g. basketball)
- Lack of awareness of integration practices
- Poor physical access to activity facilities
- Uncertainty of how to find people with a disability and target their needs/preferences
- Apprehension about the increased level of care that might be required of staff
- Transport for less mobile participants
- The perception that people with a disability do not want to participate in mainstream options. "if they did, why don't they just come down to see us?"
- Where people were living in special accommodation, difficult for carers to accommodate the variety of interests within the household, so it is avoided
- Difficulties for participants to move from disabled sporting structures into mainstream structures where the assessment of ability is subjectively governed by mainstream sporting bodies
- Lack of knowledge of the support services, programs and resources available to assist in this area

- Lack of ability to recognise a place for people with a disability in some of the more traditional mainstream options.
- Safety issues and the subsequent perceptions arising.

One of the most comprehensive overseas studies is the Sport England Survey (2002) of over 6500 people with disabilities which reported the main reasons for non-participation in physical activity as:

- Health limitations (74%)
- Lack of time (5%)
- Lack of money (5%)

Other relevant findings from this study included:

- 14% reported a negative experience in sport due to their health problem or disability – 39% of these respondents had a disability relating to their musculoskeletal system
- Of those who had participated in any sport in the 4 weeks before interview 72% said that they needed help or adapted facilities to take part in sport
- The most frequently identified ‘help needed’ was having ‘someone to keep me company’ (18%), ‘someone to advise me what I can try given my health’ (10%); and ‘someone to lead me or supervise me to ensure my safety’ (9%)

Another important study conducted in the West Midlands of England elicited the views of sport providers and people with disabilities. It identified barriers to sports participation as;

- physical access
- changing facilities
- attitudes of staff and other users
- programming,
- staff availability
- transport (French and Hainsworth 2001).

In the United States, participation barriers and supports for persons with disabilities in **fitness and recreation programs/facilities** were described in a focus group based study across ten regions (Rimmer, Riley et al. 2004). The study included consumers with disabilities (including 23 with SCI), architects, fitness/recreation professionals, and city planners and park district managers. From the 178 barriers and 130 facilitators identified, the following themes were extracted:

- the built and natural environment
- costs of participation or access
- physical, emotional and psychological barriers
- accessibility of equipment
- barriers related to the use and interpretation of guidelines, codes, regulations, and laws
- information accessibility within facilities and in advertising/promotion
- professional knowledge, education, and training issues
- perceptions and attitudes of persons who are not disabled, including professionals
- policies and procedures both at the facility and community level, and
- availability of resources e.g. transport, adaptive equipment.

The researchers concluded that the degree of participation in physical activity among people with disabilities is affected by a multifactorial set of barriers and facilitators that are unique to this population. They further noted specific barriers as:

- mobility restrictions that are often a consequence of a physical impairment
- dependence on having understanding carers and support workers
- reduced opportunities to develop friendships and community links
- diminished transport options
- need for specialised equipment and trained service providers

- reduced access to facilities and programs.

These studies illustrate that despite a range of purposes and approaches, a reasonably common broad set of constraints and supports for exercise is consistently reported for ‘people with disabilities’. While this is useful in providing general guidance, it is evident that the relative importance of these influences in the WA SCI population can only be established by enquiry and observation in the local context.

7. OTHER CONSIDERATIONS RELEVANT TO ‘PHYSICAL ACTIVITY’ AND SCI

7.1 FUNCTIONAL LIMITATION

Within the SCI population, there is a wide range in type and severity of functional limitation even within the classification of paraplegia and tetraplegia. Although, those with tetraplegia may typically encounter **more barriers** than those with paraplegia, overall function is often largely mediated by the ‘completeness’ of the injury and the presence and severity of secondary health conditions. Some studies have reported **different exercise concerns** between individuals with tetraplegia and quadriplegia e.g. (Scelza, Kalpakjian et al. 2005) noted that a higher proportion of subjects with tetraplegia reported concerns over exercise being too difficult and that health concerns kept them from exercising. Similarly, in a study of adherence to a home exercise program, people with complete tetraplegia reported the **highest frustration** with their program, and; patients with complete paraplegia, those who were elderly, and those injured longest reported the lowest frustration with their program (Manring and Kiratli 2005). In a South Australian study of 161 ‘people with disabilities’ (Edgecombe and Crilley 2002) ‘issues of importance’ when participating in community sport and recreation were associated with severity of disability e.g. those who described their disability as ‘severe’ placed most weight on **service provider knowledge/understanding**, knowing about funding sources, access to equipment, availability of **support services/personnel**, and **access to programs/services** within community groups. Those with ‘moderate’ levels of disability mostly noted provision and promotion of accurate information about ‘disability friendly’ access, amenities, venues, services and programs; while those with ‘slight’ levels of disability focused on knowing about the benefits of my participation in sport, arts and other recreation choice.

The effect of the extent and nature of limitation was further illustrated in an investigation of **quality of life** for persons with a spinal cord injury (7 with quadriplegia and 8 with paraplegia) whereby nine key themes were identified: (a) physical function and independence, (b) accessibility, (c) emotional well-being, (d) stigma, (e) spontaneity, (f) relationships and social function, (g) occupation, (h) finances, and (i) physical well-being (Manns and Chad 2001). These themes were similar for quadriplegics and paraplegics; however, physical function and independence and physical well-being affected the quality of life of persons with a quadriplegic injury to a greater extent.

Other researchers have concluded that those with greater limitations will in most cases encounter greater barriers and require more supports in order to exercise (eg (Tasiemski, Kennedy et al. 2006); Scelza, Kalpakjian et al. 2005).

7.2 AGE AT TIME OF SCI AND TIME SINCE SCI

Age at the time of and SCI event and time since that event have not been clearly separated in terms of their relationship to perceived barriers and supports. However, there is little doubt that length of time since SCI is associated with loss of function and increases in pain. It has also been suggested that “perhaps the psychological stress of chronic SCI is so wearing that, over time, regardless of knowing and being told that exercise is beneficial, people simply lose the incentive to be active” (Latimer, Martin Ginis et al. 2004).

Others have reported that although life adjustment improved throughout the years after injury, people who were older at the time of injury experienced less subjective well being, had poorer health, and less active lives after SCI (Krause and Broderick 2005). In a sample of 985 Britons with SCI those with less time since injury were more likely to continue engagement in sporting activities, and those with more years since injury were more likely to continue with more passive recreational pursuits (Tasiemski, Kennedy et al. 2006). It was also reported that those who were younger at the time of injury were more likely to continue engagement in recreational activities than those who were older.

8. CONCLUDING COMMENTS

Although the evidence about constraints and supports to structured physical exercise for people with SCI is very limited, a larger body of research has been accumulated in relation to the broader group ‘people with disabilities’ and in relation to their engagement in general ‘physical activity’.

The underlying purposes for research into this topic have ranged from testing of psychological mechanisms and models through to local policy and small-scale program improvement agendas. This diversity is reflected in the approach and methodology; the fields of study and associated literature, and in the wide-ranging reliability and validity of the ‘research’ undertaken. Consequently, no attempt has been made to make cross comparisons between findings.

However, it is apparent that there is high level of consistency in the findings, and this enables the compilation of a broad ‘pool’ of reported influences on exercise behaviour by people with disabilities and by those with SCI. These occur in many domains including functional, psychological, architectural, social, and political – specific examples of which are given in previous sections of this report. The variability of these influences within and between individuals, disability types/severity, occasions, and social and physical environments, precludes the prescription of a specific set of key variables for the local context. These need to be identified for the SCI population in various localities in WA.

International literature confirms that in SCI populations there are low levels of uptake and adherence to exercise programs, that cessation of an exercise program results in loss of any benefits gained, and that adherence to exercise programs may be particularly challenging for those with greater limitations. Given that it is very difficult for the SCI population to achieve and maintain a level of exercise that is adequate for ‘fitness’, lifestyle physical activity is now being promoted in addition to a traditional structured exercise approach.

The relationships between the identified barriers/supports, and the mechanisms by which they influence behaviour, are not well understood for people with SCI. More recent research has begun to complement descriptive utilitarian studies with a more theoretical approach that may provide explanatory and predictive potential for modifying exercise behaviour by people with SCI.

The reported research illustrates that despite a range of purposes and approaches, a reasonably common broad set of constraints and supports for exercise is consistently reported for ‘people with disabilities’. While providing general guidance for developing policy, evaluation, and research, it is evident that the relative importance of these influences in the WA SCI population can only be established by enquiry and observation in the local context.

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