

Review Article

A systematic framework to classify physical activity research for individuals with spina bifida

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Abstract

Background: Identifying the types of research conducted in the area of physical activity (PA) for the spina bifida (SB) population is important in order to move research forward to increase PA behaviors and improve health. The Behavioral Epidemiological Framework is a one way to systematically classify PA and SB literature by organizing research into one of five phases: phase 1 research links behaviors to health, phase 2 includes research focused on developing methods for measuring behavior, phase 3 research identifies factors that influence behavior, phase 4 research evaluates interventions to change the behavior, and phase 5 studies translates research into practice.

Objective: To systematically classify PA research for individuals with SB by using the Behavioral Epidemiologic Framework and to identify where the research has focused.

Method: An audit of the literature was conducted using search engines and keywords related to PA and SB. Inter-rater reliability was established between the research team coding articles based on established inclusion criteria. Finally, literature was categorized into one of the five phases.

Results: Seventy-seven articles met the inclusion criteria and were categorized. Forty three percent of the articles were categorized in phase 1, 21% in phase 2, 32% in phase 3, 4% in phase 4, and zero in phase 5.

Conclusion: The majority of articles are in phase 1, indicating that PA and SB research is still in early stages of development. Future research needs to move beyond phase 1 to examine factors that affect PA behaviors and ways to increase PA behaviors in the SB population. © 2014 Elsevier Inc. All rights reserved.

Keywords: Spina bifida; Physical activity; Health promotion; Disability

Spina bifida and secondary conditions

Spina bifida (SB) is the most common birth defect, affecting approximately 1–2 in 10,000 live births.¹ SB occurs when the neural tube fails to fuse in the embryo² and causes problems in four main areas: the central nervous system, the genitourinary tract, musculoskeletal system, and skin.³ Since the mid-1970s, there have been improvements in medical care, and individuals with SB are living longer. Consequently, the majority of the estimated 166,000 individuals in the US living with SB are adults.^{4,5}

Since individuals with SB are living longer, problems with secondary conditions are becoming more apparent. Secondary conditions are preventable conditions associated with the primary diagnosis that an individual with spina bifida is at higher risk of developing.⁶ Examples of secondary

conditions for the SB population include: obesity, cardiovascular disease, pressure sores, depression, and chronic pain.^{7–9} For young adults with SB, secondary conditions account for almost half of the health care problems in young adults with SB and are very expensive to treat.¹⁰ Due to the range of secondary conditions that can affect people with spina bifida the resultant health care costs are high, estimated to be approximately \$560,000 across the lifetime.¹¹ However, this is only an average and the costs for some are thought to be well over 1 million dollars.¹² With the growing population of adults with spina bifida, the increased risk of developing secondary conditions, and escalating health care costs, there is a great need for interventions that promote healthy aging.¹³

Physical activity and spina bifida

One method for decreasing the risk of developing secondary conditions and improving health is through physical activity (PA). The health benefits of PA are well documented,^{14–17} and PA is a leading indicator of health associated

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with decreased mortality and morbidity.¹⁸ Those who are more active have lower rates of coronary heart disease, depression, breast cancer, type II diabetes, metabolic syndrome, and stroke.¹⁸ For individuals with SB, PA is associated with more functional independence, higher quality of life,¹⁹ and higher self-worth.²⁰ Further, greater functional independence is associated with better self-management and social competence.²¹ Despite the known benefits of PA, a sedentary lifestyle is common for individuals with SB,^{22–25} thus placing individuals at greater risk of experiencing secondary and chronic conditions. Therefore, it is essential for researchers to identify the links between PA behaviors and health, and to find ways to increase PA in the SB population.

Behavioral Epidemiologic Framework

Due to the recognized need to better understand and improve the health of individuals with a disability, there is a need to understand what types of research have been conducted examining the PA behaviors of individuals with SB, and where there is a need for further investigation. One method to establish a better understanding of the types of research that have been conducted in a specific area is an audit of the literature.²⁶ Unlike a more traditional literature review, the aim of an audit is to use a framework to classify research studies into phases. Specifically, the Behavioral Epidemiological Framework is used to classify health-related research (e.g., PA behaviors for individuals with SB) into one of five phases: starting with basic research through to translating research into practice²⁷ (see Table 1). The framework has been used previously to classify PA research for individuals with a spinal cord injury (SCI) and traumatic brain injury (TBI).^{28,29}

Research in phase 1 establishes links between behaviors and health, and typically includes basic research such as dose–response relationships.²⁷ An example would be developing guidelines for PA based on the dose–response relationship between the amounts of PA individuals with SB perform and the risk of secondary conditions. Research in phase 2 examines methods for measuring the behavior, establishing the reliability and validity of measures, and field-testing new instruments.²⁷ For example, to measure PA behaviors for individuals with

disabilities, The Physical Activity and Disability Survey (PADS)³⁰ was developed and psychometric properties were assessed. Literature in phase 3 studies identifies correlates (e.g., demographic descriptors), or factors that influence the behavior, moderators and mediators of behavioral, psychological, or social variables of interest. An example of research in phase 3 would include research examining what personal and environmental barriers exist for individuals with SB to participate in PA. A second purpose of phase 3 is to test theoretical models related to behavior. Phase 4 research evaluates the efficacy or effectiveness of interventions that are focused on changing behavior. The interventions may focus on behavioral, psychological, or social variables related to health and the outcome of these studies must be a behavioral or biological marker.²⁷ A good example of phase 4 research aimed at individuals with mobility impairments is Living Well with a Disability.³¹ This was an intervention that educated individuals with the goal of promoting health and reducing secondary conditions. Finally, studies in phase 5 discuss the dissemination process of the behavioral interventions identified in phase 4. Once an intervention has been shown to be effective, it can be translated into practice in a community setting, school, home, etc. The dissemination studies may include descriptive research, adoption, implementation, or sustainability of interventions in different settings, as well as policies.²⁷ Living Well with a Disability³¹ was shown to be effective after being evaluated in phase 4, therefore was disseminated and adopted through community-based organizations throughout the United States.

Each of the phases builds off the previous phase. For example, once a relationship has been established between the behavior (PA) and health in phase 1, better methods can be explored (in phase 2) in order to refine the results of phase 1. However, the relationships between each phase may be non-linear. For example, having reliable and valid measures (phase 2) can directly impact decisions about intervention methods (phase 4).²⁷ It is important to note that the Behavioral Epidemiology Framework is a way to classify research in a given topic area and assesses the types of studies being conducted, but it does not evaluate the methodological, theoretical, or conceptual quality of the research being examined.²⁷

Table 1

Description of each phase of the Behavioral Epidemiology Framework.

Phase 1	Includes basic research that documents associations between behavior and health. Research in this phase may also include dose response relationships between the behavior and health outcomes.
Phase 2	Establishes the reliability and validity of extant measures, developing new measures, and field-tests new tools.
Phase 3	Describes demographic correlates of the behavior; how behavior varies by sex, age, etc. Research in this phase also includes examining moderators and mediators of behavioral, psychological, or social variables of interest.
Phase 4	Evaluates the efficacy or effectiveness of interventions that are focused on changing behavior. The interventions may focus on behavioral, psychological, or social variables related to health and the outcome of these studies must be a behavioral or biological marker.
Phase 5	The dissemination process of the behavioral interventions identified in phase 4. Effective interventions are translated into practice in a community setting, school, home, etc. Dissemination studies may include descriptive research, adoption, implementation, or sustainability of interventions in different settings. Studies may also examine policies and how they are implemented or maintained.

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