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Spinal Cord Injury Induced by Gun Shot Wounds: Implications for Occupational Therapy

Abstract

People with spinal cord injuries secondary to gunshot wounds present with many unique occupational challenges in terms of their overall health and well-being, and often live in violent cultures that limit occupational performance. Further awareness and understanding of this subgroup can enable occupational therapists to develop appropriate strategies needed to address the many challenges faced by this population. An in-depth understanding of cultural competence is necessary in the identification, planning, and delivery of appropriate and effective treatment. Further, a case example demonstrates the significant influence occupational therapy can achieve in this area of practice.

Keywords

Inner city, gunshot wounds, spinal cord injury, cultural competence, ethics

Cover Page Footnote

This paper is dedicated to the memory of "Darryl", who affected the lives of so many of us with and without disabilities. Your smile and your spirit live on through the lives you touched during your short time here on earth. The author would also like to thank Nova Southeastern University's PhD in Occupational Therapy Program, Darryl's OT for sharing his story, and Denny and Kathy Grace for their helpful suggestions.

People with spinal cord injuries (SCI) secondary to gunshot wounds (GSW) experience a variety of unique challenges in terms of their overall health, well-being, and diverse occupational issues. SCI induced by GSW is the third most common cause of SCI in the United States (Mayo Clinic, 2011; National Institute of Neurological Disorders and Stroke, 2013). However, little information is available in the occupational therapy literature about individuals with SCI induced by GSW, including the culture of violence that can often surround them and how this environment influences their access to resources, service utilization, and outcomes. This population is typically characterized as young adults aged 17-37 years who belong to under-resourced communities (Carrillo et al., 1998; Chopra et al., 2010; Talu, Swamy, & Berven, 2005). Although the most common causes of SCI vary among motor vehicle accidents, falls, acts of violence, and sports or recreational injuries, GSW is the leading cause of SCI among Black Americans (Talu et al., 2005). This population also tends to be males who live in inner cities and who have low education and high unemployment rates (Adkins, Hume, Nabor, & Waters, 1998; Burnett, Kolakowsky-Hayner, White, & Cifu, 2002; Carillo et al., 1998; Talu, et al., 2005). Further, the inner-city environments surrounding this group of young men are often unsupportive of healthy lifestyles and offer few opportunities for productive and meaningful social and occupational engagement (Dahlberg & Mercy, 2009). In addition, it is important to note that 90% of practicing occupational therapists are female, with 83% of

them being Caucasian (U.S. Department of Health and Human Services, 2013). An awareness and understanding of this group of young men can equip occupational therapists with strategies to address many of the challenges faced by this population. An in-depth understanding of cultural competence is necessary for the identification, planning, and delivery of appropriate and effective interventions.

Health, Social, and Occupational Issues

Culture is defined as a culmination of behaviors, beliefs, customs, values, and ways of life (Merriam-Webster, 2014). Patients with violence-related injuries are more likely to experience pain, be victims of substance abuse, have decreased support systems, have less education, earn low incomes (<\$10,000 per year), and live unproductive lifestyles (Adkins et al., 1998). Daily occupations often plague this group of individuals, as described by Lee (2012):

Most live to see another day but are riddled with injuries that transform their lives in both practical and existential ways. Gunshot victims live with bodily injuries that make sleeping, eating, going to the bathroom, working, having sex, and conducting other previously taken-for-granted aspects of daily living difficult. After the shooting, gunshot victims have problems adjusting to life in a new body. (p. 246)

In addition, because of the limited services in inner-city areas, these individuals may not receive preventive patient education on routine precautions and contraindications that have the potential to

improve their health, social, and occupational well-being. One such preventative measure includes education on the acute and long-term incidence of pressure ulcers for people with SCI, regardless of etiology.

Pressure Ulcers

Pressure ulcers are a common secondary complication for people who live with SCI. They have a drastic impact on the persons' quality of life and their immediate family members (Jackson et al., 2010). The annual incidence of pressure ulcers among patients with SCI is 23-33%, and 30% in the years immediately following their injury (Byrne & Salzberg, 1996; Regan, et al., 2009). Past studies have demonstrated that pressure ulcers are not only preventable, but that early identification can contain health care costs (Ackery, Tator, & Krassioukov, 2004). Much of the research on the prevention of pressure ulcers is focused on decreasing the incidence of pressure ulcers during hospitalization (Sinclair et al., 2004). This is not surprising, given the high incidence of developing new pressure ulcers while admitted in a hospital (Byrne & Salzberg, 1996; Dunn & Stander, 2008; Sherman, Wyle, & Vulpe, 1995). The incidence of pressure ulcers while in a hospital, however, does not address the fact that this is a lifelong risk for people with SCI. Nor does it take into account the culture, lifestyles, or access issues related to various groups with SCI postdischarge. A recent needs assessment by Chopra et al. (2010) focused on the financial burden, epidemiology, and outcomes of pressure ulcers on patients with SCI secondary to GSW. The findings revealed that there is a need to develop and

implement effective strategies for pressure ulcer prevention in order to reduce morbidity and associated health-care risks and costs in the inner-city areas of Metropolitan Detroit (Chopra et al., 2010).

Depression, Pain, and Patient Education

The literature also points to the prevalence of depression and pain as commonly reported comorbidities of SCI (Fann et al., 2011). Posttraumatic stress, anger, and denial contribute to the overall effect and present many psychological barriers for people with SCI secondary to GSW (Kroll, 2008). An unaddressed presence of depression was found to be associated with a greater incidence of pressure ulcers and decreased overall occupational performance (Fann et al., 2011). In addition, preventative education on SCI-related precautions and contraindications relating to nutrition, hydration, clean catheterization, dysreflexia, and hypotension should be a part of routine patient education protocols (Lyder & Ayello, 2008; McKinley, Jackson, Cardenas, & DeVivo, 1999). Further, Talu et al. (2005) point to the importance of providing knowledge of expected outcomes as a determinant of effective treatment. Access to the necessary education and knowledge required to live safely and successfully with SCI is a basic fundamental need for all patients.

Burden

People with SCI secondary to GSW also experience a high degree of burden postinjury (Richmond & Lemaire, 2008). When comparing violently and non-violently acquired SCI, people with violently acquired SCI experienced higher

rates of contractures, spasticity, and rehospitalization (Duggan & Dijkers, 1999). However, the root causes of this difference are likely socioeconomic status, premorbid personality traits, and follow-up health care (Duggan & Dijkers, 1999). Therefore, while the immense physical impacts of SCI pose a significant burden on the person, so too does their environmental and societal surroundings. Many who acquire a SCI secondary to GSW from a gang hit or other violent act deal with the devastation of the injury as well as the fear that surrounds their discharge from the hospital and return home to that same environment (Lee, 2013). This psychological impact on the individual is more than many can bear, especially given the vulnerable nature of this population. A groundbreaking study of suicide rates following spinal cord injuries showed that “suicide was the leading cause of death for persons with complete paraplegia and the second leading cause of death for persons with incomplete paraplegia” (DeVivo, Black, Richards, & Stover, 1991, p. 620). This points to the direct need and importance of psychological referrals and interventions, in addition to intervention for the related physical, environmental, and societal influences that impact the burden for this group of people with SCI.

In addition, the degree of financial burden affects the person, the family, and the surrounding community (Cook, Lawrence, Ludwig, & Miller, 1999; Dijkers, 1999). While this is not meant to be a generalization, it is important to address the reported impact that a lack of financial resources may have on this population. “Gunshot injury costs

represent a substantial burden to the medical care system. Nearly half this cost is borne by US taxpayers” (Cook et al., 1999, p. 447). The majority of people with SCI secondary to GSW already live in under-resourced, inner-city communities. Extensive medical costs associated with GSW pose an additional burden, further impacting access to care.

Access

Access to health care and resources for meaningful and purposeful occupational performance is critical in achieving positive outcomes from injury or illness. “Achieving positive outcomes is hampered by a lack of information about resources, access to vocational rehabilitation, peer support, and accessible housing options after discharge” (Kroll, 2008, p. 45). For people with SCI secondary to GSW, issues of access are magnified, as many of them experience additional disadvantages. Many of them do not have the financial resources or the social or professional support to access and use many supportive services, such as assistive equipment, attendant care, accessible homes, or employment (Kroll, 2008). Further, therapists are confronted with an ethical dilemma when recommending equipment for people from under-resourced communities, due to the unique physical, social, and economic challenges that factor into their daily lives (Paralyzed Veterans of America, 2008). For example, Duggan and Dijkers (1999) found that a non-violent acquired SCI group had better financial resources and access to equipment and attendant care when compared to those who had acquired SCI

secondary to violence. Therefore, it is clear that culture and environment play a large role in access to care and affordable health services. The occupational therapy profession is well positioned to address cultural and environmental barriers while taking into account the physical, social, emotional, and cultural challenges that impact participation (AOTA, 2014). Barriers in accessing necessary and appropriate health-care resources fuel restriction from and exclusion of engagement in meaningful occupations.

Physical, Social, and Environmental Access

Values, beliefs, and attitudes can lead to more performance discrepancies than actual physical barriers (Rogers & Holm, 2009), thereby hindering social participation. According to Kroll, “a complex interplay of the physical and the social and economic barriers after discharge, including housing, transportation, insurance, and family and social support” (2008, p. 47) restricts the social functioning of people who sustain SCI secondary to violence. Social barriers not only impact the patient’s ability to reintegrate, but also affect their ability to overcome basic safety and survival issues in their neighborhoods. Learning and mastering self-management skills are essential for community dwellers with SCI secondary to GSW.

Although, initially, a sense of invincibility (i.e., the gunshot had not killed them) and relief at their own survival may provide some emotional benefits, overconfident attitudes may delay active learning confidence may be lost once it becomes

clear that social and practical support is inadequate. (Kroll, 2008, p. 47)

Further, limited social support and reintegration make vocational achievements difficult to obtain. While medical precautions and comorbidities require focused attention and education, so too does the social structure that often initially discharges patients with SCI secondary to violence with a lack of social support and awareness of vocational services (Kroll, 2008).

People with SCI secondary to GSW or other violent acts reported a high degree of difficulty physically negotiating the world around them, and attributed the presence of physical barriers as preventing them from having full access to their homes and communities (Duggan & Dijkers, 1999). The community environment posed the most significant issues for people with SCI secondary to GSW, as a lack of community access led to poor satisfaction and impacted engagement in productivity and social and community activities (Rintala, Hart, Priebe, & Ballinger, 1998).

Environment, Health, and Occupation

Living and working environments play a critical role in the overall health and well-being of individuals. A supportive environment enhances various aspects of life, whereas an unsupportive or dangerous environment often leads to negative outcomes. According to Rintala et al. (1998), community integration consists of three essential components—social integration, community participation, and community resource utilization. In addition, socioeconomic status has a direct influence on access to necessary resources and

services, and therefore has important implications for the community reintegration process (Rintala et al., 1998). Therefore, it is absolutely critical that occupational therapists are part of a team that works toward modifying environments to improve the overall health and well-being of this population.

The question remains, how do we affect change to better position people with SCI secondary to GSW? Rintala et al. (1998) reports that the ultimate goal of rehabilitation centers is to deliver the necessary “knowledge, appropriate assistive equipment, sufficient financial resources, and needed education and skills, and if the physical and social environments are accessible, then individuals with SCI are more likely to be able to become fully integrated into the community” (p. 16). Successful recovery and social reintegration, however, are highly dependent upon timely and comprehensive rehabilitation (Kroll, 2008). The Occupational Therapy Practice Framework III (OTPF III) (AOTA, 2014) discusses various outcome levels, including aspects that address the person and their surrounding environment. For example, the Canadian Occupational Performance Measure (COPM) is a semi-structured interview tool designed to provide a patient-centered functional outcome measure (Law et al., 1990). Further, incorporation of the COPM along more traditional rehabilitation measures, such as the Functional Independence Measure, has been shown to illustrate the importance of including more patient-centered scores, such as satisfaction with and performance of occupations into the SCI plan of care (Donnelly et al., 2004).

It is essential to address immediately preventative health that is inclusive of medical precautions and contraindications for people with SCI. There is a need to ensure proper availability and education of discharge instructions for people with SCI. An inclusive educational program must provide knowledge and understanding of nutrition, hydration, clean catheterization, dysreflexia, hypotension, skin inspections, pressure relief, and signs and symptoms of pressure ulcers and urinary tract infections (Lyder & Ayello, 2008; McKinley et al., 1999). Education must include an active learning phase where the patient (and family, if applicable) is required to demonstrate their learning both verbally and physically in each of these areas. Therefore, education and training for both the patient and the available family caregivers—depending upon their unique living situation—is necessary to ensure successful therapeutic outcomes. A follow-up home visit after initial discharge allows assessment for further home modifications, assistive technology, and equipment to ensure mobility and independence within the home environment. Further, screening and referral for depression and pain need to be a part of this educational program in order to address symptoms and increase awareness. Finally, culturally competent training needs to occur at the personal and organizational levels in order to ensure therapists have the knowledge and understanding to prevent stereotyping, assumption of similarities, and language biases in order to encourage cross-cultural communication (Office for Victims of Crime, 2013). Cultural competence is essential in creating

effective treatment plans, referrals, and recommendations, while increasing awareness of other major barriers, skills, strategies, and resources (Ekelman, Bello-Haas, Bazyk, & Bazyk, 2003; Office for Victims of Crime, 2013).

Occupational therapists must address physical, social, and economic barriers that limit care; accessibility in the home, workplace, and community; and psychological well-being with appropriate referrals for multidisciplinary care. Community integration and vocational rehabilitation need to be assessed properly and referred when appropriate. “An individual’s history of antisocial behavior, level of education, and employment history appear to be the most important factors in community integration, other than actual impairment and disability” (Adkins et al., 1998, p. 26). Social support and community involvement not only have a positive effect on the health status of people with SCI, but are important to their self-esteem and overall affect (Anson, Stanwyck, & Krause, 1993). Programs, such as peer-mentoring and second-look, can provide the needed support and resources that are often missing in the lives of so many living with SCI. The purpose of a peer mentor is to provide emotional support, knowledge, and resources to patients as they attempt to rebuild their lives, and peer mentors have been found to be invaluable to many with SCI in acute (Ljungberg, Kross, Libin, & Gordon, 2011) and long-term stages (Boschen, Tonack, & Gargaro, 2003). The Christopher and Dana Reeve Foundation is an example of a resource that provides information on peer mentors, as well as many other resources,

including helpful websites, books, and publications specific to SCI secondary to GSW. Further, The Rehabilitation Institute of Chicago (RIC) is well known for their second-look programming, for which the primary purpose is to reach out to people with SCI years after they have acquired it. The RIC model consists of assessments and recommendations for people with SCI every 18-24 months, and is focused on the prevention and management of complications from SCI (RIC, 2014).

Ethics

In direct relation to the Occupational Therapy Code of Ethics (AOTA, 2010), the principle of non-maleficence seeks to ensure services and appropriate transition of services. This speaks to the direct need for occupational therapists to properly assess and refer people with SCI secondary to GSW to the appropriate and needed services. Principle three refers to autonomy and confidentiality in terms of establishing a collaborative effort with service recipients to understand fully the services and potential for risks and benefits (AOTA, 2010). Also, whereas making every effort to advocate for services was originally placed under beneficence (AOTA, 2005), the revised 2010 code moved advocacy for occupational therapy services and the need to take action by means necessary to obtain it under a new and highly controversially defined principle of social justice (“Social justice: To be or not to be,” 2011). Beneficence and non-maleficence discuss the basic fundamentals of collaborative efforts to create a culture of trust, advocacy, and

confidentiality between the therapist and patient, which is essential for people with SCI secondary to GSW. “To foster successful community reintegration . . . the clinician must rely on accurate disclosure of information and thus must establish a measure of trust” (Adkins et al., 1998, p. 26). This leads us back to the principle of beneficence and the need for occupational therapists to take the necessary steps to educate themselves through formal and informal continuing education, in order to ensure that services are delivered in a competent manner within our scope of practice (AOTA, 2010). Competency in practice as well as in culture is an essential prerequisite for all health care professionals working with vulnerable populations. Additional terminology, rules, or protocol changes in our profession's Code of Ethics cannot replace or enforce that which is a truly inspired effort on behalf of a clinician with good character and sound judgment. In this world of political correctness and divisive debate over social and occupational justice, the following case example demonstrates what the pure commitment of an occupational therapist can achieve in this area of practice.

A Case Example

Darryl (alias) was 15 years old when he acquired a SCI secondary to GSW while playing at a friend's house in an inner-city area. Darryl's friend was showing off his father's gun when it accidentally discharged into Darryl's neck, causing a complete C-4 SCI lesion. Darryl did not have insurance and was treated and discharged to live at home with his father, as his parents were divorced. Darryl's family could not afford attendant care, but

he did have a large family of brothers. Therefore, he was moved around from house to house in order to receive informal caregiver assistance for his basic daily care. Darryl did not return to school, due to the physical barriers of transportation and the side effects of pain and depression that he experienced daily. Ten years later, he was hospitalized for a late-stage pressure ulcer. The occupational therapist initially assigned to him did not know how to help him. Joe, the occupational therapist who eventually took over the case, relates, “Darryl never got the attention he needed. Everyone assumed he couldn't finish high school or do anything. Given the total dependence of the patient and his limited awareness of available technology and the means to obtain it, the OT assigned to him did not know what to do with him, so he asked me to help.” With the social worker's help, Darryl applied for Medicaid. Joe helped Darryl come up with fundraising events and explore alternative funding sources, including assistive technology (AT) firms that donated products to Darryl. He lived in the inner city where he eventually rented a house and had a bedroom set up on the first floor. He had attendant care for about 8 hr per day, compared to the 24-hr care that is typically afforded to those with access to other reimbursement streams. Joe helped Darryl get involved with AT, and provided him with the necessary patient education on the health care basics of SCI. Joe recalled, “Things like basic health education that you thought would be a given, weren't.” In a collaborative effort with a treatment team that now included a rehabilitation engineer and vocational counselor, Darryl eventually

completed his High School Grade Education Development (GED) while in therapy and began working at Ticketmaster as a sales agent, with a fully adapted workstation. He eventually was hired at a local university, where he shared his case study, allowed students to interview him, and provided assistive technology evaluation and recommendations. Darryl also taught basic computer training and Dragon Naturally Speaking for occupational therapy students, and similar training for patient populations under Joe's direction and supervision. Unfortunately, his health started to decline. "Living alone and not having 24-hour care caught up with him." A pressure ulcer took a turn into septicemia, and ultimately caused his death. Darryl was in his early thirties when he passed away.

This case provides the typical illustration of a young, single, Black American, un-employed, un-insured male, with less than a high school diploma who lived in an inner-city area when he sustained a SCI secondary to GSW. After ten years of living from home to home and caregiver to caregiver in an inner-city area, Darryl's eventual hospitalization brought him to an occupational therapist who was able to advocate for him and to implement change by exposing Darryl to various skills, knowledge, and occupations. Darryl was able to then use his life experiences and lessons to impact change in others who faced similar barriers, while teaching occupational therapy students the value of each individual, no matter their circumstance. While it did not seem like Darryl had much to offer or many

resources from which to draw, Joe saw more than an individual with SCI secondary to GSW. He saw Darryl's light and was able to capture that light and help him engage in a meaningful, purposeful life.

Summary

Capturing the light that exudes from each individual, no matter what his or her circumstance, is a key aspect of occupational therapy. People with SCI secondary to GSW often live in less than desirable circumstances. However, a set protocol to address the basic fundamentals of SCI education and occupational opportunities early on can be easily adapted to fit the unique needs of each individual. Preventative health is a major focus of the HealthyPeople.gov (2014) 2020 campaign, where it is reported that access to preventive care impacts preventable death, quality of life, and the overall physical, social, and mental health status of individuals. Occupational therapists can provide the access and opportunities needed to engage these individuals in meaningful, productive lives. Inner-city trauma is related to lifestyle and often takes on a chronic, recurring nature (Sims et al., 1989). "Culture can be a moving target and understandings of culture, occupation, and the individual are necessarily complex" (Bonder, 2007, p. 19). Due to the nature of this culture and the recurrence of medical complications, ongoing follow up and advocacy are essential to implement the supports needed to successfully seek and engage in purposeful and meaningful occupational performance—the premise of the occupational therapy profession.

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