

Community Integration for After Acquired Brain Injury: A Literature Review

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This paper reviews the current literature on acquired brain injury (ABI) with a focus on ABI burden, importance of community integration, and community integration definitions suggested by the literature. Acquired brain injury (ABI) is referred to a diverse range of disabilities resulted of injury in different parts of the brain. People with ABI are in face with different aspects of individual, family and social concerns or burdens which directly affect their lives. Although community integration as an ultimate aim of rehabilitation is optimal approach to overcome their consequences, a comprehensive concept of it is always challenging. There are several different definitions for community integration including various aspects of life with ABI. Living with brain injury constitutes an expanded experience of community isolation and consequences which reduces participation and social integration. Community integration is aimed to condense concerns of people with ABI with returning them to community .

Key words: acquired brain injury, community integration, inclusion

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Introduction

Acquired Brain Injury (ABI) is defined as an “injury to the brain which results in deterioration in cognitive, physical, emotional, or independent functioning. ABI can occur as a result of trauma, hypoxia, infection, tumor, substance abuse, degenerative neurological disease or stroke. These impairments to cognitive abilities or physical functioning may be either temporary or permanent and cause partial or total disability or psychosocial maladjustment” (1). ABI has high incidence globally. It is evident that the number of people with ABI is growing globally because of the high incidence of accidents, stroke, infection, alcohol and drug abuse, and degenerative neurological disease which are common causes of ABI. A recent meta-analysis shows that the prevalence of traumatic brain injury in the general population in the US is about 12-16% in the males and 8.5% in females (2). In 2003, around 113,300 people (0.6% of the population) were living with an impairment caused by ABI in Australia. Of these, 75,200 were younger than 65 years which is 0.5% of

the population in that age group (3). It is expected that with the high incident of car related accidents in Iran (4), the incidence of acquired brain injury is high. Life expectancy of those with moderate disability decreases by four years and life expectancy of people with severe disability is much lower than people without ABI (5). This paper is a review of the current literature with a focus on ABI burden, importance of community integration and definitions suggested by the literature.

Burden of ABI

There is a wide range of needs for this group of people in the community. In 2008 in Australia, long term care costs for moderate traumatic brain injury (TBI) were estimated to be \$300 million and \$962.5 million for severe TBI (6). ABI is a very complex condition. The complexity of brain injury and its consequences originates from several reasons. Impairment to the brain, which is a crucial component of the main part of nervous system, may result in physical, sensory, cognitive and psychosocial/emotional disabilities or a

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combination of them. The impairment can be temporary or permanent, and result in partial or total disability and psychosocial maladjustment (7). The severity of the brain injury may be classified based on clinical severity according to length of amnesia (e.g. using Galveston Orientation and Amnesia), level of consciousness (using Glasgow Coma Scale), mechanism of injury (i.e. penetrating versus closed head injury), and morphology (8). The severity usually is classified as mild, moderate and severe. The more severe the brain injury, the more complex long-term impairments that may follow (8).

Consequences of ABI

Depending on the severity and nature of the injury, the level of disability differs. The personality of the person prior to the incidence of ABI and the amount of support the person receives from other people after the incidence add to this complexity. The person's personality may change dramatically, affecting relationships with family/previous friends (9-11). Some hidden impairments such as memory or cognitive problems, fatigue, and difficulties in decision making can be particularly challenging for individuals and their families (12). Dawson and Chipman (13) studied adults with ABI and found that approximately 90% had social integration limitation; in other words, they were disadvantaged relative to their able-bodied peers in social relationships.

The social consequences of ABI are evident in the Australian context. In 2006, about 30% of people with specific activity limitations or participation restrictions who were of working age (between 18 and 64 years) were unemployed. This figure was much higher than people with no limitation (one out of 13 people) (14). As reported by Brain Injury Australia (cited in Brain Injury Australia, 2009b, p.5) participation in the workforce (employed or looking for a job) is much lower for people with ABI (36.5%) than people with disability generally (53.2%). It is reported that people with ABI have a considerably higher unemployment rate (18%) compared to people with a disability (11.5%) generally, and people without a disability (7.8%) and their main or only income source for many is governmental support (15). The consequences of ABI are extensive at the individual level. People with ABI often demonstrate multiple and complex treatment needs arising from physical, cognitive, emotional, and behavioural problems, that extend beyond discharge from acute, hospital based

rehabilitation (16). Inadequate community support results in significant additional responsibility on their caregivers including their families (17). The consequences of ABI also constitute an increasing family, health, and social burden. There is strong evidence that ABI has long-lasting consequences for the family members (12,18). One third of family members, who act as caregivers, demonstrate depression, anxiety and adjustment disorders (19-22). The caregiver burden is associated with severity of ABI and increases over time (23,24). There is a strong relationship between cognitive, behavioural, and emotional changes in the person with ABI and the level of stress in the caregivers and relatives (25). The wide range of types of impairments resulting from ABI creates very diverse support needs (26). The total cost of traumatic brain injury in Australia was estimated to be \$8.6 billion in 2008. The economic burden of people with ABI who do not return to productive life and rely on social resources is quite substantial. In Australia in 2008, years of healthy life lost due to disability for traumatic brain injury were an estimated 15,703 (6).

Importance of Community Integration for people with ABI

People with ABI experience limitations such as cognitive, emotional, psychosocial, and physical impairments as a result of brain injury which dramatically affect different aspects of the individuals' lives (27). Returning to the community and having a productive life after brain injury is the most important rehabilitation objective (28-30). It is a human right to participate as a member of the community (31,32). Full and effective participation and inclusion in society, Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity, Equality of opportunity and Accessibility are some of the rights that the United Nations considers as key rights of people with disabilities (32). Despite this acknowledgement, there are many young people with disability due to brain injury who live in aged care centers or other forms of institutional care. This includes people with relatively low levels of disability. A study in nursing homes (33) showed that this obvious human need to live in the community is not met for many people with ABI in Australia. In the research on 330 young people with disability resident in nursing homes, Winkler, Farnworth, and Sloan (33) found that living in nursing homes for these people created social isolation. About 44% never or only

once a year, received a visit from a friend, and only 24% were visited by a relative on most days. Twenty one percent of participants rarely, or not at all, went outside of their rooms. In addition, most of the activities provided in services were not appropriate for the young people and they had no interest in sharing common meal space with the older residents. For most of these people, the nursing homes are not the most appropriate place to live. This issue has been addressed by Australian Government recently. From July 2006, the Australian Government has provided funding of up to \$244m for a five-year program to provide age appropriate care for this group of people and to move them to more appropriate settings (34).

Historical review of community integration

Since the early 1970s, the social and political focus to close institutions has resulted in more attention from health service providers and researchers to the concept of community integration. A strong focus on clients is needed to support them to be integrated into the community in order to use their productive skills in society, to help them live independently, and to reduce community expenditure (35). At the time, the concept of community integration was generally addressed as physical presence rather than being part of the community socially and psychologically (36). Later in that decade, community integration was acknowledged as a right for people with disabilities (32,36) and many were returned from institutes to live with their family; however this movement put the burden of care on the families and other caregivers (17,37). These problems commonly arose because people with ABI were returned to a community which was not suitable for their needs and was not ready to accept them (38). Different aspects of impairments resulting from ABI pose great difficulty for families in terms of acceptance and adjustment (22). Rejection and related problems were reported to be a source of stress which increased feelings of self-deprecation that, in turn, caused lower self-esteem in people with ABI (39). A systematic review showed that return of persons with severe disability to their family life had a negative effect on the quality of life of their family members (18), loss of partnership, leisure time, and social contacts (40,41). The concept of returning to home is fundamental but not sufficient for the process of community integration. Both deinstitutionalization and normalization refer to the fact that all individuals have the right to live within their communities, to achieve autonomy, have choice, freedom, dignity, and respect (42,43). Normalization is the “use of culturally

normative means to offer person’s life conditions at least as good as that of average citizens, and to as much as possible enhance or support their behavior, appearances, experiences, status, and reputation” (43). Dijkers (44) described institutionalization and community living as two extremes of community integration. One extreme is institutionalization where people are limited to the ‘institute’ and have no relationships with the world outside. An example for this situation is living in an institute where the person is limited as a result of a severe physical or mental impairment. The other extreme is ‘living normally in the community’. Dijkers claims that the ‘normal’ community living is not easily definable. He also adds that normal personal relationships in the community are dependent on the persons’ characteristics (e.g. age, gender, and culture) and quality and quantity of the relationships can be extremely different from one person to another. Nirje (45) provided a contrast between life in institutional settings and life in the community. He identified several aspects of the normalization principle for people with intellectual disability, some of which can also be applied to all disabilities. These aspects include having a normal routine (e.g., getting out of bed in the morning), the normal rhythm of day (e.g., going to bed at an age-appropriate time), the normal rhythm of life (e.g., holidays and special family days), having personal choice, wishes, and desires respected, living in a bisexual world rather than in mono-sexual settings, having normal economic standards (e.g. having a job and income) and living in a typical home setting rather than an isolated, hospital-like setting.

The concept of ‘social role valorization’ (SRV) also provides rationales that promote community inclusion and participation (46,47). SRV focuses on the achievement of valued social roles for people who are, or are at risk of, social devaluation (48). Having a valued social role increases the possibility of having a good life (49). One strategy to enhance social value for people with a disability is to promote a positive image and avoid situations that reinforce negative social roles. A second strategy is to improve the person’s competencies so that they can participate actively and productively in the community. These strategies can be carried out in different levels. At the personal level, for example, the development of competencies will contribute to access to valued roles. The competencies might be developed when the person participates in the family and community and has relationships with other people. Competency enhancement in family and in bigger social groups like the neighborhood and with

friends might have a significant effect on the individuals' valued social roles. Third level strategy is enhancement of general public knowledge about persons with disability which can provide opportunity for the person to find/act in valued social roles (50). Human rights, normalization, deinstitutionalization, and social role valorization are all concepts that emphasize providing opportunity for all people to live and actively participate in the community.

Definition of community integration

The importance of community integration was highlighted by the World Health Organization in its policy "Health for All by the year 2000" which was described as "all people in all countries should have at least such a level of health that they are capable of working productively and participating actively in the social life of the community in which they live" (49). People with disabilities want to be able to participate in community activities like ordinary people without being labelled according to their disability (51) and in a community-based setting rather than being isolated to rehabilitation settings (52).

While the concept is not new, there is no consensus on the meaning of community integration (53-55). Diverse operational definitions have been used for systematic reviews, designing outcome measures, and/or defining the main objectives of community integration programs. For example, a systematic review of effectiveness of rehabilitation programs for people with ABI defined five areas of 'community reintegration' as independence and social integration, caregiver burden, satisfaction with quality of life, productivity, and return to driving (McCabe et al., 2007). Another systematic review aiming to find predictors of community integration and appropriate outcome measures (56), considered Dijkers (44) definition having priorities and opportunities in the least restrictive environment as the operational definition of community integration for their study. In the design of community integration programs, the definition is often narrowed down to a single, or few aspects of community integration. For example, several programs focus on vocational rehabilitation (27,57,58) or return to driving (59,60).

Different dimensions are identified by researchers for community integration. Review of 17 studies of persons with psychiatric disabilities living in the community concluded that most definitions are unidimensional and only considered 'physical presence' as the most important indicator for community integration (61). Wolfensberger (47,62)

suggested two dimensions, including both physical and social integration. Occupation, residential environment, social support, and overall satisfaction (63)(Halpern, Nave, Close, & Nelson, 1986); leisure participation, family contact, and acceptance (64,65); and social engagements, interactions with neighbors and other members of community, and sense of belonging (66) are further examples for dimensions of community integration identified by different researchers. The most common dimensions of community integration are relationships with others, participation in activities, and living independently. McColl (67) considered nine indicators in four domains for community integration including general integration (orientation, conformity and acceptance); social support (close and diffuse relationships); occupation (productivity and leisure); and independent living (independence and living situation). Dijkers (44) defined community integration as independence in decision making, productivity and relationships with a range of people. He believed that the roles of the person should be age/gender and culturally appropriate. This view was also supported by other authors (29). Willer, Rosenthal, Kreutzer, Gordon, and Rempel (68) considered participation in home-like settings as important as engagement in social network and occupation. Some authors (67) consider community integration as 'living independently'.

The most recently published descriptive community integration framework is the Community Integration Framework (CIF) which was drawn from views of five stakeholder groups including practitioners, researchers, policy makers, people with acquired brain injury and family members (69). The CIF was designed using a Delphi method, an iterative process of surveys, interviews, and focus groups. This framework includes seven themes: Relationships, Community Access, Acceptance, Occupation, Being at Home, Picking up Life Again, and Heightened Risks and Vulnerability. The CIF as the most comprehensive framework for community integration can be used as a basis for development of community integration programs and outcome measures.

Conclusion

Acquired brain injury, as a globally common condition, has dramatic impact in individual, family and society levels. Community integration for ABI has been of interest of many researchers and therefore there are several definitions for this term. Significant gaps remain in our understanding about community integration programs and their outcome.

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