Community Reintegration and Quality of Life in Rehabilitated South Indian Persons with Spinal Cord Injury

Author: Samuel Kamalesh Kumar*, MOT, DR (OT), Co-authors: Vinoth Kumar.C**, Jerome Dany Praveenraj***

Key Words: Return to work, Activities of Daily Living, Social integration, Occupation, Mobility

Abstract

Aim: To explore the level of Community reintegration and Quality of Life of rehabilitated South Indian persons with spinal cord injury.

Method: A cross-sectional survey was conducted on 100 participants to explore the level of community reintegration using CHART scores as the outcome measure and QOL was assessed using WHOQOL-BREF.

Results: The participants have scored better community reintegration scores in physical independence (97 ± 8), social integration (96 ± 10) and cognitive independence (94 ± 14). Similarly, better scores noted in all the domains of WHOQOL- BREF: Physical health (16 ± 3), Psychological (17 ± 3), Social relationship (16 ± 3) and Environment (17 ± 2). The correlation between community reintegration and quality of life is too low. Demographic variables do not have any influence on community reintegration and quality of life except the occupation and education level.

Conclusion: Community reintegration and Quality of Life of rehabilitated South Indian persons with spinal cord injury were good. The comparison between community reintegration and quality of life showed low correlation indicating that the increase in community reintegration may slightly influence the quality of life.

Introduction

Spinal cord injury (SCI) is one of the most common severe disabilities which negatively influences physical and psychologic aspects of health and QOL.\(^{1-4}\) It is generally a debilitating disorder that can have a profound impact on independence and lifestyle, related to loss of motor and sensory function as well as associated problems such as bladder, bowel, sexual dysfunction, chronic pain, increased risk of mental health problems, increased risk of re-hospitalization, relationship and marital difficulties, and poor vocation prospects.\(^{1, 6, 9-13}\) Therefore, restoring persons with spinal cord injury to their optimum level of functioning and participation and improving their quality of life are essential goals of a rehabilitation program.\(^{16}\)

Community reintegration leads to life satisfaction as well as a sense of competence and is essential for psychological and economical well being and skill development. It helps people to make friendships, gain knowledge, learn skills, express creativity and determine purpose and meaning of life. Greater community reintegration promotes better overall adjustment and improves one’s quality of life.\(^{17}\) Community reintegration is not only important in restoring QOL; poor community reintegration is associated with higher mortality rate in SCI.\(^{18}\)

The CHART is one of the most commonly used measures to quantify community reintegration in SCI.\(^{19}\) CHART evaluates key domains of community reintegration. These domains are physical independence, cognitive independence, mobility, social integration, occupation, and economic self-sufficiency.\(^{17}\) A typical nondisabled person scores 100 on each domain, while the person with maximal handicap scores 0. It takes approximately 15 minutes to administer. It can be used with persons having a range of physical or cognitive impairments. There is quite adequate evidence for reliability and validity of the CHART.\(^{20}\)

The WHOQOL-BREF was developed to provide a measure that considers both the components and determinants of health and well-being. The profile emphasizes individuals’ physical, psychological, and spiritual functioning; their connections with their environments; and opportunities for maintaining and enhancing skills (WHO). The WHOQOL-BREF contains a total of 26 questions. The WHOQOL-BREF has good to excellent psychometric properties of reliability and validity.\(^{21}\)

For the last 60 years, our SCI rehabilitation center founded by a physiatrist with paraplegia has been providing national rehabilitation services that include a structured 3-month inpatient...
protocol in a university hospital setting in a small South Indian town. The purpose of this study is to find the level of community reintegration and its relationship with quality of life of rehabilitated South Indian persons with SCI from our rehabilitation center.

Method

Participants:
The participants for this study were previously rehabilitated community-dwelling persons with SCI. More than 1000 persons with SCI have been rehabilitated in our center over the last 20 years. Four hundred and fifty persons who live within a 100-km radius of the rehabilitation center are being followed up in the community. Of these, 32 have died, 22 have been lost to follow-up and 100 persons have been followed up with home visits in the year of the study. Of the other 296 persons with SCI who were invited for the annual follow-up program, called “Rehab Mela,” 140 attended the follow-up program, and 100 participants consented to participate in this study. Study procedures were approved by the university institutional review board.

Study Design:
A cross-sectional survey was done to explore the level of community reintegration using CHART scores as the outcome measure and QOL was assessed using WHOQOL-BREF. CHART and WHO-QOL BREF was administered by experienced occupational therapists.

Intervention:
The intervention at the rehabilitation center included the following elements: functional mobility, bowel and bladder management, caregiver training, vocational training, and discharge follow-up.

The functional mobility goal for persons with SCI above T6 is wheelchair independence. For those with SCI below T10, it emphasizes independence in ADLs and functional ambulation with knee-ankle-foot orthoses and elbow crutches. This program defines functional ambulation as a walking speed of 20m/min and an endurance (walking without stopping) of 500m[22]. Independence in bowel and bladder management using digital evacuation and intermittent clean catheterization is taught with an emphasis on social continence[23]. The caregiver training in this center emphasizes that a family member should stay with the person with SCI throughout the rehabilitation program. Thus, later on this family member becomes a key support to the person with SCI in the community.

Weekly language-based support groups for persons with SCI and family members are also an integral part of the rehabilitation process[23]. These sessions are carefully planned so that each person with SCI and their carer are able to discuss a range of practical issues related to stress, anger, anxiety, management of their future with relation to change of roles, vocational settlement, and community reintegration. The approximate cost of this inpatient program excluding food and medicines is around Rs. 40,000 and is often self-paid because no government or insurance facility is available for rehabilitation in our country.

After this, a 6-month residential vocational reintegration program is offered with an emphasis on self-employment[24]. This program offers self-employment options like tailoring, cycle repair, toy making, greeting card making, cane handicraft, and carpentry[25]. This self-employment model is provided because government policies and legislation for employment of persons with disability are still not enforced in our country.

After discharge, follow-up is offered to all persons with SCI within a 100-km radius. Four hundred fifty persons with SCI are under our follow-up, of which 70% live in rural communities with roads and houses that are inaccessible to wheelchairs. There are very few employment opportunities available for persons with disability. Very few economic benefits are provided by the government in the community. Home visits are conducted by the rehabilitation team annually for around 120 persons with SCI. The remaining patients are invited to a 3-day residential weekend for an annual follow-up, which includes various activities like medical evaluation on the first day, recreational and sports activities on the second day, and peer interaction, spiritual and motivational activities, and other competitions on the third day[23].

Data Analysis:
The data analysis was done using SPSS for Windows. Community reintegration and QOL was quantified using the mean and standard deviation of each CHART and WHOQOL-BREF domains. Pearson correlation coefficient test and regression analysis was used to compare the relationship between the CHART and the WHOQOL-BREF domain scores. The t-test was done to compare the relationship between the CHART and the WHOQOL-BREF domain scores based on the demographic variables. The alpha level was set at .05.

Results
Table 1 shows the demographic details of study participants. Out of 100 participants 51 (51%) were below the age of 40, 92 (92%) were men, 57 (57%) were married, 83 (83%) were occupied, 70 (70%) were educated below 10th standard and 93 (93%) were paraplegics.

Table - 2 shows the level of community reintegration and QOL derived from the study participants. Lower scores indicate less community reintegration. Participants have showed better community reintegration scores in physical independence, social integration and cognitive independence domains whereas lower scores in occupation, mobility and economic self sufficiency domains. This table also shows QOL of participants. Lower scores indicate poor QOL. Participants have showed better QOL in all four domains.

Comparison of CHART and WHOQOL domain scores showed statistically significant relationship (p = 0.036) but the correlation between these two is low (r = 0.210). Further regression analysis also showed significant relationship (0.036). As one unit increase in level of reintegration there is .025 units increase in QOL.
Table 1  
Demographic variables of the study participants

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age(y)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 40</td>
<td>51</td>
<td>51</td>
</tr>
<tr>
<td>&gt; 40</td>
<td>49</td>
<td>49</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>92</td>
<td>92</td>
</tr>
<tr>
<td>Women</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>57</td>
<td>57</td>
</tr>
<tr>
<td>Single/Widow/Widower</td>
<td>43</td>
<td>43</td>
</tr>
<tr>
<td>Occupation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupied</td>
<td>83</td>
<td>83</td>
</tr>
<tr>
<td>Not Occupied</td>
<td>17</td>
<td>17</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 10th standard</td>
<td>70</td>
<td>70</td>
</tr>
<tr>
<td>&gt; 10th standard</td>
<td>30</td>
<td>30</td>
</tr>
<tr>
<td>Level of injury</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paraplegia</td>
<td>93</td>
<td>93</td>
</tr>
<tr>
<td>Tetraplegia</td>
<td>7</td>
<td>7</td>
</tr>
</tbody>
</table>

Table 2  
Comparison of Community Reintegration (CHART) and Quality of Life (WHOQOL - BREF) scores

<table>
<thead>
<tr>
<th>CHART</th>
<th>Mean ± SD</th>
<th>WHOQOL - BREF</th>
<th>Mean ± SD</th>
<th>‘r’</th>
<th>p value</th>
<th>REGRESSION ANALYSIS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Physical health</td>
<td>16 ± 3</td>
<td></td>
<td></td>
<td>Beta</td>
</tr>
<tr>
<td>Physical Independence</td>
<td>97 ± 8</td>
<td>Psychological health</td>
<td>17 ± 3</td>
<td>0.210</td>
<td>0.036*</td>
<td>0.025</td>
</tr>
<tr>
<td>Cognitive Independence</td>
<td>94 ± 14</td>
<td>Social relationship</td>
<td>16 ± 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Integration</td>
<td>96 ± 10</td>
<td>Environment</td>
<td>17 ± 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupation</td>
<td>75 ± 33</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mobility</td>
<td>68 ± 18</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Economic self sufficiency</td>
<td>57 ± 41</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Significance at 0.05 level; r = Pearson correlation coefficient; SD = Standard Deviation

Discussion
The mean scores of individual CHART and WHOQOL domains reflect the level of community reintegration and QOL in persons with SCI who were residing in rural South India. Participants showed better community reintegration scores in the domains of physical independence, cognitive independence, and social integration in CHART and also showed better QOL in all the domains of WHOQOL in spite of their economic constraints, minimal support from government and other non-governmental organizations, and the presence of architectural barriers in the community.

Physical independence CHART scores measure the degree to which an individual requires assistance with medical and self-care needs. A score of 97 ± 8 in physical independence indicates a high level of integration in this domain. Out of 100 participants 93 were paraplegics, who were functionally ambulant. The more distal the spinal cord lesion, the greater the degree of functional independence in terms of daily activities. Because a majority of the participants were functionally ambulant, they achieved better scores in physical independence domain. This emphasizes the importance of achieving functional ambulation in patients with paraplegia.

The social integration CHART scores describe a person’s
interaction with family members, friends, and business associates. We found that the social integration score was 96 ± 10. This rehabilitation program emphasizes the responsibility of the family. The presence of large and extended families provides essential physical, emotional, and economic support to family members with disabilities. The sense of belonging is the most cherished goal, and isolation and social rejection are avoided through social visits, which are an important aspect of life and strengthen family and social ties. The high score in the social integration domain could be attributed to family support. The data suggest that an emphasis on family involvement in SCI rehabilitation might contribute to better social integration.

The cognitive independence CHART scores measure the degree of supervision or assistance required to make decisions and handle money. The mean score of cognitive independence was 94 ± 14. Persons with SCI in our population experience a loss of autonomy in the family and restrictions to decision making and money handling, and many depend on family members for financial decisions. In spite of these factors, higher cognitive independence scores have been reported, which could be because of their self-employment through our residential vocational reintegration program. This program also provides vocational guidance, counseling, and support that enable them to return to work, which in turn may help reduce their dependency on others. Although self-employment through our residential vocational reintegration program may be getting people back to work, it may not be providing sufficient earnings for some.

Occupation CHART scores measure the number of hours of work, education, voluntary services, or leisure undertaken by the person with disability. Participants have scored 75 ± 33 in this domain. 83% of our participants returned to work after SCI. Recent studies have shown that working rates for persons with SCI vary from 31% to 48%. The low CHART score may be because of those who returned to work did not return to their previous job due to personal and environmental barriers but adopted self-employment options in home-based occupations that often did not require 8 hours of work per day.

The mobility CHART scores describe the persons’ ability to
access their environment and participants scored 68 ± 18 in this domain. Personal factors such as motivation, physical status, psycho-social issues, complications of SCI, ability to perform transfer from bed to wheelchair, toilet transfer, crutch transfer, and ability to walk using orthoses play an important role in achieving high mobility scores. However, Environmental factors such as presence of barriers in accessing public places, buildings, transportation, and private residences also play an important role in achieving high mobility scores. Most of the personal factors mentioned above are addressed in our rehabilitation program, whereas the environmental factors remains a challenge. Houses, public places, and transport in this part of the country are rarely accessible to persons with disability. Moreover, making houses barrier-free is the responsibility of each person. Thus, despite a good mean score for physical independence, we have noted lower CHART scores for mobility.

Economic self-sufficiency CHART scores measure the availability of financial resources and the economic independence of the family. Participants scored 57 ± 41 in this domain. This population lives in rural areas where the primary economic activity is daily wage labor. Often the person with SCI was the sole breadwinner in the family. Although many participants had 5 or more years of formal education, only around 30% achieved higher education, compounding the challenge for economic self-sufficiency. However, information derived from the economic self-sufficiency domain of CHART should be interpreted with caution, because economic self-sufficiency is extremely sensitive to the figures of poverty level and costs of income, and expenditures reported by the participants may be questionable.

The participants’ quality of life was measured using WHOQOL-BREF. The participants have showed better quality of life scores in all the domains which are physical health 16 ± 3, psychological 17 ± 3, social relationship 16 ± 3 and environment 17 ± 2. The result of this study was contrary to the findings of previous studies, which reported lower QOL scores in persons with SCI. These studies have reported that physical loss, physical role limitations and social restrictions are a major problem after SCI which potentially affects the personal health and QOL. Our participants were independent in their home, able to contribute substantially in the family decisions and well supported by the family members which was reflected in the CHART scores. All these factors could have contributed for better QOL.

The comparison between CHART and WHOQOL scores showed low correlation between them. Lower scores in occupation, mobility and economic self-sufficiency domains of CHART would have influenced the relationship between CHART and WHOQOL. The results would have been better if comparison made between individual CHART domains and overall WHOQOL.

A comparison of WHOQOL and CHART domain scores based on age, gender, marital status, occupation, education and level of injury showed significant relationship only in CHART scores based on occupation and in both WHOQOL and CHART scores based on education. This is consistent with the findings of the previous researches which reported that, less education being consistently associated with greater handicap and vice versa and higher education predicts higher life satisfaction and quality of life. Factors such as completeness of injury, sex, age at injury, and time since injury have been inconsistently found to be related to lower QOL.

Conclusion

Community Reintegration and QOL of rehabilitated South Indian persons with SCI were good in spite of their economic constraints, minimal support from government and other non-governmental organizations, and the presence of architectural barriers in the community.

The limitation of our study was that there was no control group, so we have no real way of knowing that these outcomes were related to our rehabilitation program. Therefore, expansion of level of community reintegration and quality of life survey for persons with SCI using CHART and WHOQOL-BREF in other centers should be conducted to compare the efficacy of our comprehensive SCI rehabilitation program.

References


