

ORIGINAL ARTICLE

Return to work and school: a model mentoring program for youth and young adults with spinal cord injury

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Study design: This is a prospective study.

Objectives: Young individuals with spinal cord injury (SCI) need support to actively participate in the community after their injuries. The 'Back on Track' mentoring program was developed to match mentees with SCI with mentors to assist with post-injury adjustment. The objectives of this study were to improve the percentage of youth and young adults with SCI, who access post-secondary education or employment opportunities and to improve quality of life.

Setting: This study had a community-based setting.

Methods: Each mentee with SCI was matched with a community-based mentor, with or without a disability. The mentoring relationship was planned for 2 years. Participants were evaluated with standardized questionnaires at intake, at the time of post-secondary education or employment entry and 4 months post entry.

Results: In total, 39 individuals with SCI, age 16–26 years, were enrolled. Average age of mentees was 19.8 years (s.d. = 3.0). In total, 29 participants were matched with mentors, and 10 participants (34%) completed the program, with seven (24%) returning to school, two (6.9%) returning to work and one individual (3.4%) attending school part time.

Conclusion: Although multiple barriers to success occurred, this program demonstrated that it could assist the youth and young adults with SCI to obtain post-secondary education and employment. This type of support system should be encouraged in order to improve the quality and satisfaction of life for young adults with disabilities.

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Introduction

Significant improvements in medical management and rehabilitation for individuals with spinal cord injury (SCI) were made in the past several decades. The emphasis of rehabilitation is shifting from medical management of acute conditions to the challenges that affect quality of life (QOL) and community reintegration, including employment and attaining a higher level of education. Return to work has often been looked at as an indicator of successful rehabilitation after SCI. On the basis of the National Spinal Cord Injury Statistical Center Database, overall average rate of employment for individuals with SCI in the United States in 2008 was 22%.¹ Other studies from the US, Denmark and Norway have reported post-injury employment rates between 13 and 70%.^{2–6}

The situation for youth and young adults with disabilities, aged 16–26 years, can be particularly disheartening as their vision of themselves as full and active participants in society is typically not fully formed at onset of their disability. One of the strongest predictors of return to work following a disability is a history of employment pre-disability;^{7–10} a fact that may not be true for the majority of individuals with disabilities in this age group. Indeed, many of the individuals in the targeted age demographic may not have even finished high school or may be in transition between high school and post-secondary education.^{11,12} Furthermore, these individuals are still in the process of forming their own concept of self, which can be radically altered because of the disability. A second strong predictor for successful return to or attainment of work is the level of education. For those individuals who have higher levels of education, it is less difficult to return to work after disability.^{2,11,13–15}

Coming to terms with disability, and conceptualizing a 'different' future from what may have been previously conceived, are tasks that confront the young adult with SCI. Although systems and services may be in place to assist

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individuals, it can be very difficult and confusing to navigate the requirements, applications and follow through the procedures needed to successfully access services. However, it is incumbent on each individual to take the initiative to access programs and resources in the community. Frequently, much time and effort is wasted with duplicative and incorrectly focused endeavors. Previous research indicates that many individuals with SCI do not receive adequate information regarding employment support and resources available to them.¹⁶

To address this gap in service delivery, 'Back on Track' mentoring program was established to improve the community integration of individuals with SCI between the age of 16 and 26. The concepts and practice of mentoring programs in different populations have been studied extensively. Mentoring programs have potential to maximize full integration into society, employment, independent living and economic and social self-sufficiency of individuals with disabilities. With the knowledge of resources within their community, provided by mentors, young adults with SCI can be encouraged to fully participate in social, academic and employment-related activities, improving their QOL. For individuals with SCI, there have been only few studies that examined 'supported employment', and they indicate that supportive employment approach may reduce barriers for return to work.^{17,18} The objective of this mentoring intervention was to improve reintegration of individuals with SCI within an age group that has typically not yet established a solid post-secondary education or employment history.

Materials and methods

This project was reviewed and approved by the Research and Human Subjects Review Committee at Santa Clara Valley Medical Center. The program was funded by Rehabilitation Services Administration, and participants were recruited from 2005 to 2010, with the intent that each mentoring relationship would exist for up to 2 years. Subjects were enrolled if they were between the age of 16 and 26 years. Other inclusion criteria included motivation of return or transition to post-secondary education or community-based employment.

Program staff consisted of two physicians, Program Coordinator, Program Assistant, Vocational Counselor, and Rehabilitation Psychologist. The Mentoring Program Coordinator monitored progress of the relationships on a semi-monthly basis and served as liaison to a Vocational Rehabilitation Counselor. Each mentee was matched with a community-based mentor with or without a disability, although efforts were made to recruit mentors with SCI. Mentors underwent a training curriculum and refresher sessions throughout the program under the facilitation of a Rehabilitation Psychologist. Structure was based on traumatic brain injury/SCI Peer Support training at our facility. Mentor/mentee relationships were required to have a minimum of three contacts/month through in-person, telephone or electronic-mail methods.

At enrollment, an intake form was completed, including age, gender, ethnicity, level of education at injury,

occupational status at injury, time post injury and specification of productive activity goal—transition to post-secondary education or employment. At the end of the program, mentees completed a satisfactory questionnaire. Follow-up assessments were also conducted 3 months after entry to the program, every 3 months thereafter, at the time of attempted entry to post-secondary education/employment and 4 months after entry to post-secondary education/employment. Standardized assessments at enrollment and each follow-up were: Disability Rating Scale Employability and Level of Functioning; Participation Index of the Mayo-Portland Adaptability Inventory—Version 4 providing an assessment of the ability to participate in the community; Supervision Rating Scale assessing the level of supervision required on a daily basis; Craig Handicap Assessment and Reporting Technique—Short Form providing an indication of involvement across multiple domains of International Classification of Functioning; and Diener Satisfaction with Life Scale. These assessment measures have been well described and validated in previous disability-related studies.

The program exit criteria were not time-limited, as every person who entered the program progressed toward community integration, post-secondary education and/or employment on his/her individual timetable. A successful completion of the program for each mentee was defined as entry to post-secondary education/employment. This, by no means suggested that the mentor/mentee relationship necessarily ended at this point, but that it could continue outside the auspices of the formal mentoring program.

Results

In total, 39 individuals with SCI aged 16–26 years enrolled as mentees (Table 1). In total, 17 mentors were employed, 11 in school and 7 retired. Four mentors were matched twice with mentees. Among the enrolled mentees, 29 (74.4%) were matched with mentors. In total, 10 (34%) completed the program with seven (24%) returning to school, two (6.9%) returning to work and one (3.4%) attending school less than half time. Seven (18.0%) dropped out of the program before being matched. Four mentees continued an on-going relationship with their mentors after the program. Three mentees could not be matched before the conclusion of the matching period. Mentees who were matched, but dropped out before completion, were in the program for an average of 5 months (s.d. = 4.2). Reasons for not completing included: substance abuse, loss of patience, incarceration, becoming mentors themselves and starting work/school before being matched. Average to be matched, from the time of enrollment, was 210 days (s.d. = 241.2). The average time of mentees' participation in the program was 17 months (s.d. = 5.2) (Table 2).

In total, 13 participants (44.8%) were employed pre-injury, with four (30.8%) completing the program; whereas 16 participants (55.2%) were unemployed pre-injury, with six (37.5%) completing the program. There was no significant difference in the success rate based on employment pre-injury (Fisher's exact P -value > 0.99). For those who completed the program, the average time post injury

Table 1 Demographics

	Enrolled in the study	Matched with mentors (% of enrolled)	Completed the study (% of matched)
Total	39	29 (74.4%)	10 (34.5%)
Male	28	23 (82.1%)	6 (26.1%)
Female	11	6 (54.5%)	4 (66.7%)
Average age, years (s.d.)	19.8 (3)	19.9 (3.9)	20.3 (3.7)
16–17	9	6 (66.7%)	3 (50%)
18–21	18	14 (77.8%)	4 (28.6%)
22–26	21	9 (42.9%)	3 (33.3%)
<i>Ethnicity</i>			
Caucasian	12	8 (66.7%)	4 (50%)
Hispanic	21	15 (71.4%)	4 (26.7%)
Asian	0	0 (0%)	0 (0%)
African American	4	4 (100%)	0 (0%)
Other	2	2 (100%)	2 (100%)

Table 2 Number of mentees and the length of time they participated in the program

0–3 months	0
4–6 months	0
7–9 months	1
10–12 months	0
13–18 months	6
19–24 months	3

was 328.20 days (s.d. = 451.19) versus 366.86 days (s.d. = 1078.20) for those who did not complete the program ($P = 0.99$)

The QOL was measured using Craig Handicap Assessment and Reporting Technique, Disability Rating Scale, Participation Index of the Mayo-Portland Adaptability Inventory—Version 4, Supervision Rating Scale and Satisfaction with Life Scale. For all mentees who were matched with mentors, regardless of whether they were successful in completing the program, enrollment data were compared with the last measurements obtained from the mentees using paired Student's *t*-test (Table 3). For the mentees who completed the program, the final measurements were taken 4 months after completion of the program. For the mentees who dropped out, the measurements are from the last 3-month follow-up. There was a trend for improvement in the cognitive independence measure ($P = 0.066$) of Craig Handicap Assessment and Reporting Technique and in Disability Rating Scale ($P < 0.001$), but not in any other measures. With mentees who successfully completed the program, more improvements in the QOL measures were found. There was a trend for improvement in cognitive independence ($P = 0.082$) and occupation measures ($P = 0.096$) of Craig Handicap Assessment and Reporting Technique, and statistically significant improvements were found with Participation Index of the Mayo-Portland Adaptability Inventory—Version 4 ($P < 0.05$), Disability Rating Scale ($P < 0.01$) and Supervision Rating Scale ($P < 0.001$), but not with the Satisfaction with Life Scale ($P = 0.535$). In addition, we surveyed the subjects about their satisfaction with the program. In total, 90% of the subjects said that their participation in the program was a positive experience; they

Table 3 Comparison of quality of life outcomes between the mentees who completed the program versus all mentees matched with mentors

Outcome measures	All mentees P-values	Mentees who completed the program P-values
CHART physical independence	0.691	0.136
CHART cognitive independence	0.066	0.082
CHART mobility	0.537	0.125
CHART occupation	0.344	0.096
CHART social integration	0.163	0.649
M2PI total score	0.126	0.016
DRS	0.000	0.000
SRS	0.116	0.005
SWLS	0.845	0.535

Abbreviations: CHART, Craig Handicap Assessment and Reporting Technique; DRS, Disability Rating Scale; M2PI, Participation Index of the Mayo-Portland Adaptability Inventory—Version 4; SRS, Supervision Rating Scale; SWLS, Satisfaction with Life Scale.

will participate in this program again; and they plan to stay in touch with their mentors.

Discussion

Unemployment in individuals with SCI remains a serious and prevalent problem, which is particularly disturbing given that employment positively affects QOL and longevity.¹⁹ With improvement in morbidity/mortality after SCI, employment rate is being recognized as one of the primary markers of successful rehabilitation outcome.² In addition to physical status, emotional status, such as optimism and self esteem, and psychological variables can significantly impact the rate of return to work after SCI. In fact, satisfaction with life is significantly correlated with employment compared with income and even the level of impairment or disability itself.⁹ Higher levels of education have been correlated with higher rates of employment; those with higher levels of education are less likely to obtain manual labor jobs, a more difficult classification of jobs for individuals with SCI to obtain post injury. Thus, not only employment itself but also

obtaining higher levels of education was considered another objective of this study.

Peer support has been the primary intervention providing psychosocial support to individuals with SCI. Social support usually implies interactions with family, friends and peers. It has been shown to have a positive effect on emotional status, physical health and QOL for individuals with different types of disabilities. In addition, there are many different types of 'support', such as informational, emotional or instrumental.²⁰ Informational support encompasses providing education, assistance in decision making and feedback. Emotional support consists of acceptance, love or opportunity for honest and open communication. Instrumental support consists of provision of resources, assistances or services. With this mentoring program, the primary goal was not only to provide social support but also to encompass all forms of support. Efforts were made to match the mentees with mentors with SCI in our study; as from our experience through years of facilitating peer support programs, all aspects of living with SCI were thought to be better addressed by mentors who themselves have SCI. However, among the 24 mentees matched with an SCI mentor, eight of the 24 were successfully completed the program (33%), whereas among the five mentees who were matched with an able bodied mentor, two of the five mentees completed the program (40%). Given the relatively small sample size, it is difficult to conclude the impact of having a mentor with SCI.

In this study, for mentees who were matched with mentors, 34% were successful in returning to school or work, which is similar to other published employment rates.¹⁹ As the average time post injury for this study was less than 1 year, it may be more appropriate to compare the rate of employment in our study with the 1-year post-injury data from the National SCI Database. For comparison, we undertook further analysis of the SCI National Database, in individuals with SCI in the same age group as this study (16–26 years old); 28.0% were in school and 8.8% were employed at 1 year post injury. It should be noted that our program also had more mentees returning to school (24%) compared with those returning to work (6.9%). The rate of employment remains low, and may be explained by the fact that the financial situation and employment opportunities have not been ideal for several years even in the general population.

Previous studies have reported that younger age and time post injury positively associated with employment rate after SCI,² but this may be because the younger individuals have longer time to work toward employment and thus, have better rates in the long term. For example, the rate of employment for individuals 2–5 years post injury had an employment rate between 18–32 versus 44–54% for those more than 25 years post injury.² Therefore, the relatively low rate of employment in our study may be due to the limited time post injury.

Similar to previous literature on mentoring, QOL measures improved significantly in this program overall by being matched with mentors, but improvement in the QOL was more so with mentees who were successful in returning to

work/school. We also measured satisfaction of our program; and our program was rated to be satisfactory by 90% of our mentees who completed the program. Unfortunately, we were not able to get satisfaction information from those subjects who did not complete the program. The survey of mentees who completed the program indicated that the mentees would have liked more structured or scheduled activities with the mentors, including group activities, so that the encounters between the mentees and mentors would not be completely left up to the mentors and mentees.

Difficulties that we encountered with matching mentees with mentors were various. We tried to match a mentee with a mentor who had a similar disability, interest and who lived in the same county, because we felt that the relationship would have a better chance to thrive. Some mentees lost interest while waiting to be matched and dropped out of the program. A few were successful in going back to school or being employed before being matched.

Barriers to completion of the program after mentees were matched were more difficult to overcome, even though the program tried to address the barriers our mentees faced. For example, not only did the mentees have access to their mentors but also there were a vocational rehabilitation counselor, rehabilitation psychologist and members of the program staff who were accessible if needed. Unfortunately, some mentees' issues were out of the scope of the program and several mentees had to be dropped from the program. Common reasons for incompleteness of the program were: lack of motivation, prioritizing therapies and rehabilitative exercise before the program, denial of disability, family crisis, gang affiliation and substance abuse. Unfortunately, we do not have follow-up information on these mentees who did not complete the study, as the most common reason for incompleteness was 'lost to follow-up.'

Limitations of our program included availability of mentors, especially those with SCI, being limited in certain communities. The mentees and mentors did not utilize the vocational counselor and the rehabilitation psychologist as much as expected. It was also unclear whether the mentors encouraged the mentees to use existing community agencies for assistance. Even though mentors were given instructions to interact with mentees at least three times/month, it was difficult to track how much and what type of interactions were happening between mentees and mentors. The participants were also only followed for 4 months post attaining their goals, so it is unclear whether the mentees continued their relationship with their mentors and whether they were able to maintain employment or schooling long term. Given that it often takes a long time for an individual with SCI to be employed, the maximum time set for each relationship of 2 years may be too short to expect significant improvement in the employment rate.

Although this program supported the participants only through attainment of employment or enrollment in post-secondary education, it is known that ongoing 'follow-along' services are important to maintain employment.¹⁹ Future programs need to be expanded to include continuous follow-up support after an individual attains the initial goal of employment or enrollment in post-secondary education.

Conflict of interest

The authors declare no conflict of interest.

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