

**POST - TRAUMATIC ADJUSTMENT INTERPOSING FACTORS OF SPINAL
CORD INJURY (SCI) SURVIVORS IN THE KENYAN EDUCATION SYSTEM**

WINFRED MUGURE*
PRISCILLA W. KARIUKI*
GATHOGOMUKURIA*

*University of Nairobi: Nairobi, Kenya

Abstract

Spinal cord injury survivors are confronted with a psycho-social crisis of a high magnitude. Such people, most of who are either paraplegic or tetraplegic find themselves limited not only physically; but also psychologically. The inability to access or continue with education not only limits their scope and career prospects, but also reduces their chances to perceive their prognosis positively and adjust accordingly. Consequently, they are unable to critically think about and transform their lives and impact society by becoming self-reliant, independent and creative. As a result, most of them remain less empowered, possessing marginal prospects. This article is drawn from a study which sought to examine the extent to which physical disability, fragile emotional disposition and poor socio-economic infrastructure militate against the spinal injury survivors' education integration endeavor. The spinal cord injury survivors' prominent challenges and their impact on the realization of their educational goals were examined. This paper concentrates on the interposing factors in SCI survivor adjustment. Three hundred and fifty two spinal cord injury survivors of school going age (16-35 years), registered under the Kenyan Paraplegic Organization, were interviewed. The research design employed in this study was descriptive survey. Two instruments, the structured questionnaire and scheduled structured interview were used to collect data. The data realized was analyzed using SPSS descriptive statistical methods. The main finding of the study is that post traumatic psychosocial adjustment, which is partly determined by the emotional disposition, affects reintegration into the education system.

Keywords: Adjustment, Interposing Factors, Spinal Cord Injury (SCI)

Introduction

UNICEF (2006), established that adverse psychological effects of SCI, socio-economic effects of ill-health, post-traumatic dysfunctions, as well as poor infrastructure have marginalized spinal injury survivors reducing their chances of getting reintegrated into the education system. As a result, such survivors face unique and distinctive psycho-social

and developmental challenges as they try to adjust and handle life expectations. The UNICEF survey (2006) outlined the consequences of the failure to get reintegrated into the education system and submitted that such failure yields personal and situational characteristics which include emotional and socio-economic strain, rendering the survivors dependent and unresourceful. The survivors' physical limitations also get amplified by emotional and social factors. The lack of such integration also precipitates isolation and a decrease in emotional resilience and morale (Gosney, 2011).

Lack of educational empowerment becomes the survivors' greatest disability; makes them vulnerable and exposes them to deprivation and exclusion, inhibiting their holistic recovery- physical, mental and emotional (Fabes, 2012). In a study by Wheels for the World among Japanese SCI earthquake survivors, Groot (2012) indicated that circumstantial pressure subjects such survivors to lack of self-esteem, competence, personal power and inner strength that would enable them to explore other avenues of self-development. As a result, they are deprived of basic needs which include; physiological, safety and esteem needs which inhibit the achievement of self-actualization as stipulated in Abraham Maslow's (1943) theory of motivation. According to Anderson (2009), permanent disability on its own predisposes survivors to stress and alienation. If their goals in life such as those achieved through education are not met, their challenges may become insurmountable. They may often become confined by feelings of depression, frustration, anxiety and helplessness. Others may end up getting desolate, devastated and incapable.

Studies of SCI survivors' potential, challenges and dispositions with regard to self-development have been done in the United Kingdom, Australia, India and Mexico. According to the World Health Organization (WHO) report (2013), these studies indicate that psychosocial empowerment and availability of learning opportunities (formal and informal) can profoundly influence the survivors' lives and development in a multitude of ways. A recent survey by UNICEF (2011) for instance reported remarkable socio-economic empowerment, positive self-image and independence among survivors who had been anchored emotionally and managed to access learning opportunities. A 2008 study conducted by Cathey Hart Natalspruit hospital, Transvaal, indicated a high rate of clinically significant signs of depression among trauma patients in general.

While in the United States of America, resumption of learning for SCI survivors is a readily available option, it is not the case in the developing world (Holtz 2010). A study by the World Health Organization (2001) indicated that most survivors in Kenya do not meet the

expectation of living a full and decent life in dignity, self-reliance and integration. The study set precedence for a number of surveys and case studies which have been done in an effort to address structural and infrastructural requirements. Following such studies, the disability Act 2003 which provides legislation that ensures increased access to barrier free environment, education and employment of people with disabilities was enacted.

The needs and challenges of SCI survivors are varied and wide ranging. A study carried out at the Jefferson University Hospital in Philadelphia (2008) indicated that such challenges may include social isolation, difficulty in coping with the expectations, family and peers; weak relationships with others, low self-esteem as well as difficulty in making decisions. The survivors may also fail to take care of their own physical and medical needs. As a result, such survivors get fixated and miss out on personal growth and fulfillment. Basing his projection on Maslow, Brigford (2012) stipulates that the inability to fulfill basic needs on the lower cadre inhibits the successful movement to the higher level ones that enhance creativity, spontaneity and problem solving, empowering survivors into independence.

According to Anderson (2009), these factors which can be labelled as poor 'post care' which includes emotional and social interventions plus infrastructure that inhibits their mobility as well as accessibility do militate SCI survivor adjustment and resumption of learning. This has been compounded further by the nature of the SCI condition which is a devastating neurological injury, resulting in varying degrees of paralysis, sensory loss and sphincter disturbance which are permanent and irreversible in most cases (Klause, 2008). The condition requires regular and consistent medical and psychosocial follow up which further drains the survivors of their energy. Given the wide range of challenges projected, SCI survivors may require intervention measures which underscore integration in the education system (WHO, 2013). Barriers to this endeavor which include poor socio-economic and non-conforming infrastructure as well as fragile emotional dispositions require attention as a matter of priority. There is marginal documentation of information on the effects of SCI generated psychosocial challenges on survivors' personal development endeavors in Kenya. However, poor post injury care management, weak socio-economic infrastructure and lack of professional psychosocial support have formed a solid barrier limiting survivors' access to empowerment programs as projected by the United Nations standard rules for equalization of opportunities (2010). Such programs are the avenues through which survivors would broaden their perspective, ensuring a healthy emotional disposition, self-development and independence. The physical deficits that result from SCI require long periods of hospitalization; some of

which could run for several years. This inadvertently leads to the exhaustion of all their resources in hospital care; as a result of which finances for psychosocial support and empowerment programs essential for the determination of their future become unavailable. For this reason, most lead a life characterized by dependence, marginal prospects and uncertain future.

A study by the Preventive Medicine Council in the US (2006) confirms this impact by recognizing that SCI places the individual at a high risk of psychological disadvantage and affects self-image and self-management. This study which examined the relationship between SCI and negative psychological state by examining 1,946 SCI survivors used the Spielberger Trait Anxiety Inventory and discovered that 54% of the survivors had an elevated level of negative psychological state. This is comparatively lower than the 61.5% in this study but similarly, the study further attributed low self-esteem and fragile decision making skills, which account for poor planning for the future, to the imbalance resultant to spinal injury. In some states, for instance, post care follow up includes placement in learning or vocational training institutions to step up skills to meet market demands (Crowell, 2009). The study further submits that such empowerment revives lost hope and gives survivors course to pursue their life goals.

A 2006 survey carried out by the U.S synovate consumer panel established that 79% of respondents in a survey sampling 11,000 spinal injury survivors reported that they had been fully integrated back to their initial social economic roles including formal schooling and paid employment while 08% were tetraplegics whose injuries had impaired all their limbs. Majority of the tetraplegics had reportedly learnt supplementary skills such as writing and painting using their mouths, 11% were self-employed, while 2% were bedridden (Warren,2004). A similar study conducted in Scotland underscored the need for holistic rehabilitation that enhanced personality development and independence (Preventive medicine,2007).

Statement of the Problem

Education empowerment awareness for people living with disabilities, for example spinal injury survivors has grown exponentially however, they continue to be marginalized. statistics at the Kenyan Paraplegic Organisation indicate that out of 869 registered spinal injury survivors, only 4% possess marketable skills (KPO 2011). The ability for SCI survivors to invest in personal development is heightened by several factors. These comprise but are not limited to financial constraints resulting from the implications of medical treatment,

especially for families living in slum areas who are already affected by abject poverty (Barker,2009). The nature and structure of poverty in such households is more complex than average standards as stipulated by WHO in a paper on Health and Poverty reduction reduction covering the 2007-2017 (WHO,2007). The structure of poverty is also quantitatively different and is not limited to deficiencies in basic consumables alone. While such families survive below the official poverty line, living in thoroughly squalid conditons with basic necessities barely provided for, the survivors find it comparatively difficult to keep up with medical follow up and rehabilitation (WHO, 2007). As a result, personal development through learning is denied priority and pushed to the background. This is inspite of education empowerment being the key to a healthy disposition and social economic independence as stipulated in a UNESCO report (2010). The survivors' inability to access learning limits their chances for self-empowerment and also makes them miss out on participating in community development. The current study carried out in Nairobi Kenya in 2017, sought to investigate if SCI causes an elevated level of negative psychological response among survivors, to an extent of impairing their potential to set a personal development agenda.

Importance of Study

This article is only part of a study expected to generate a heightened awareness of the plight os SCI survivors in terms of factors which hinder their post-traumatic adjustment. It further aimed at assisting in the establishment of psychosocial interventions specific to SCI survivors; in an endeavor to reintegrate them. Furthermore, the understanding of SCI post trauma issues can facilitate the translation of knowledge to inform reintegration best practice guidelines for the survivors.

Objective

This article handles only one objective from the main study. This objective aimed at determining factors that affect post - traumatic adjustment of SCI survivors in the education system.

METHODS

This study utilised an expost facto research design which Tuckman (1978) describes as one where the study investigates the variables without any manipulation. The target population included 364SCI young survivorswho acquired SCI before the age of 21 and meet the inclusion criteria of the Kenyan paraplegic organization. The data was collected using a

structured questionnaire and interview schedules for the psychosocial caregivers and SCI survivors respectively.

Participants

The data on table 1 indicates those SCI survivors who were recruited from different geographical locations including urban at 36.9% paraplegics and 19.6% tetraplegics. The rates rise progressively from upper end to unstructured settings which could be attributed to the socioeconomic dynamics.

Table 1

SCI survivors level of function by geographic location

Residence		Paraplegic	Tetraplegic
Urban	Upper-end	09 (2.6%)	05 (1.4 %)
	Middle	23 (6.5%)	09 (2.6%)
	Lower end	4 (11.6%)	16 (4.5%)
	Unstructured settings	57 (16.2))	39 (11.1%)
	Total	93 (36.9%)	69 (19.6%)
Peri-urban		58 (16.5%)	21 (6.0%)
Rural		55 (15.6%)	19 (5.4%)

Out of the four urban settlements levels, the unstructured setting recorded the highest rate 16.2% and 11.1% for paraplegics and tetraplegics respectively. This could be attributed to the comparatively low cost of living.

RESULTS

As indicated on table 2 of the SCI survivors who are engaged in gainful employment, 27.5% are in formal employment, 7.5% in temporary employment while 65% are self-employed. Temporary employment involves working from home in engagements such as data entry and editing. Self-employment of SCI survivors may be attributable to challenges of employability or the flexibility which is afforded by self-employment. Self-employment includes activities such as crochet and hand embroidery work as well as tuck shops and mobile vending. Due to low incomes associated with these kinds of employment none of the survivors had been able to make any investments. This finding significantly contrasts that of Kruse (2006) who submitted that 48% of the survivors could work and support themselves fully.

Table 2 Source of income

	Frequency n=120	Percentage %
Formal employment	33	27%
Temporary employment	09	7.5%
self-employment	78	65%
Investments	Nil	-
Total	n=120	100%

n=120

The study also established that SCI survivors also lacked fundamental provisions. A percentage of 60.5% had to terminate rehabilitation therapy at some point while 27.6% had to contend without crucial medication due to lack of financial resources. Some of the SCI-survivors at the rate of 25.3% had to shelf their basic education ambitions for the same reasons. A few (7.4%) had to do without food, 6.5% lacked resources for hired residence and 13.1% struggled for clothing. The finding underscores the high cost of SCI management; leading to the resources of the SCI survivors getting depleted.

Figure 1 presents data on social adjustment of the SCI survivors as rated by the psychosocial caregivers. A few, (22%) of the survivors' level of adjustment was rated as very good and the highest percentage of 36% as average/fair. Almost all the respondents in 1st and 2nd clusters were attached to a rehabilitation provision with a psychosocial caregiver. As such, the level of adjustment could be attributed to such encounters. A few respondents (14%) were reported to have poor social adjustment; 28% of them, who were categorized as "co-operative" were on special programs geared to aid their adjustment problems.

The data revealed that several barriers inhibit reintegration into the education system. Table 3 presents the findings as articulated by the psychosocial caregivers.

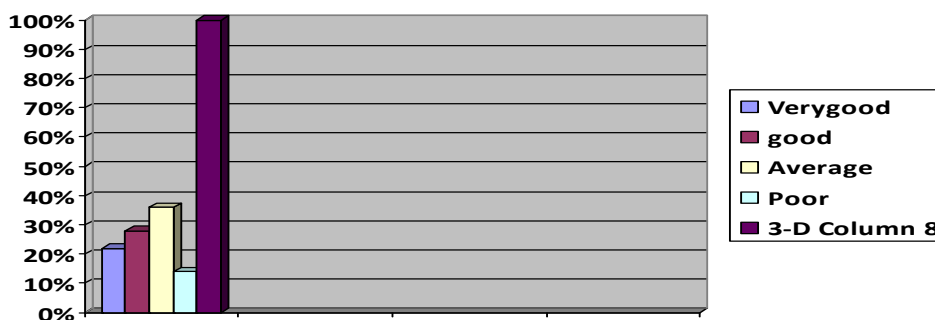


Figure 1: Social Adjustment

Socio-economic factors were identified as the highest ranking barrier at 82%. This can be attributed to the high cost of SCI management which may deplete the resources. Lack of transportation at 74%, this is closely related to poor or lack of functional equipment at 38% because the transportation infrastructure was said to affect the durability of functional equipment like wheelchairs. Health related concerns at 48%, biases such as stigma and poor mainstreaming at 32%, and limited functional ability at 28%. Apart from the limited functional ability, all the other barriers identified can be mitigated which underscores the need of psychosocial support.

The study found out that some SCI survivors changed status in their occupation to suit their post-injury condition. The data shows that a majority of the survivors 32.6% stopped working after the injury. Another 17.4% changed from being employed to self-employment. The findings on these two clusters of survivors could be attributed to rigid and long working hours and infrastructural barriers that limit accessibility including the public transport system. Other survivors were able to negotiate for changed responsibilities with the same employer at 13.5%. This is an indication of post injury-empowerment. A few (5.1%) changed employers while 8.0% changed the nature of their personal business to suit their post injury functional status. A low percentage of survivors (1.1%) changed from self-employed to getting employed because their self-employed ventures were no longer tenable. These study findings differ from Franceshini (2003) who reported that among the survivors in his longitudinal study, 35.6% survivors had changed jobs, 61% were able to leave home on daily basis and 36.5% could leave home only with assistance. The score of those who attained autonomy was 6.5 out of 16. (Franceshini et. al, 2003).

Table 3 Barriers to reintegration into the education system

Barriers	Rate
Lack of transportation	74%
Socio-economic factors(e.g lack of finances for education)	82%
Poor or lack of functional equipment(e.g. high cost of medical equipment and supplies)	38%
Health related concerns	48%
Biases such as stigma and lack of mainstreaming	32%
Limited functional ability	28%

The SCI survivors reported feelings of anger, guilt, helplessness, bitterness and worry. Figure 2 indicates guilt is comparatively rare at 28% and actually, mostly affected road traffic

accident survivors who were driving themselves at the time of accident. Almost half (42%) recorded feelings of anger; the anger may be attributed to post injury frustrations. The survivors also tend to feel helpless and bitter at 64% and 72% respectively while a very high percentage of 86% is preoccupied by worry. Findings are consistent with the research findings by Katharine (2012) which found out that most SCI survivors exhibit negative injury related feelings especially worry, anger, guilt and helplessness. Although the results of Katharine's study differ marginally in the rates of manifestation, the recommendations project toward the need for psychosocial therapy.

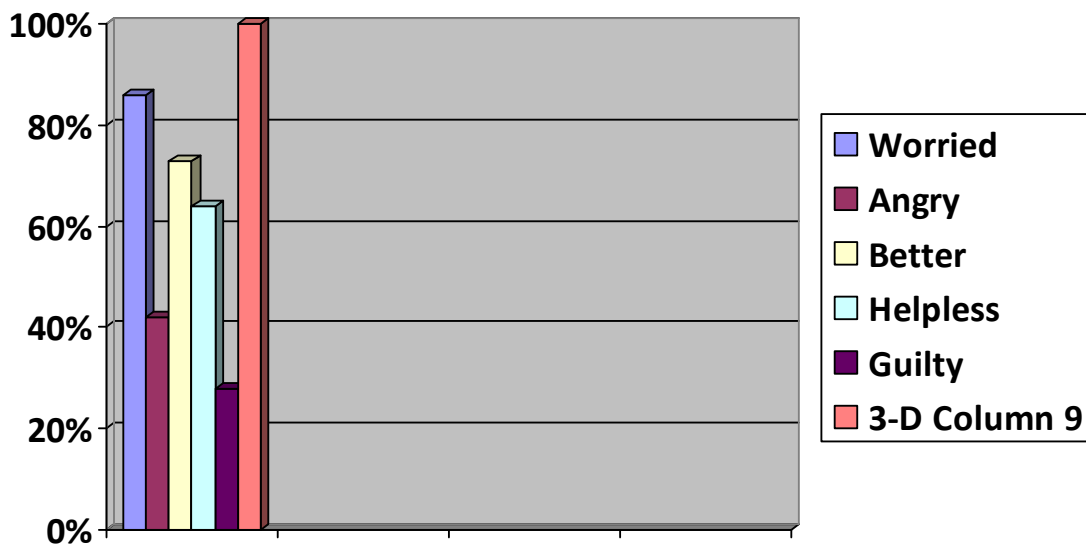


Figure 2: Injury-related Feelings

CONCLUSIONS AND IMPLICATIONS

SCI is a catastrophic injury with potentially devastating impacts including far reaching physical, social and psychological consequences which inhibit reintegration into the learning system. The study for instance established that many survivors develop severe negative emotions in response to the injury which normally affect post trauma adjustment. Yet, positive attributes of coping were stronger predictors of post-injury adjustment than were negative ones. Results highlighted the importance of psychosocial care and support in post-injury adjustment of SCI survivors in order to interrupt the post trauma concerns.

The study revealed that the effects of psychological adjustment on the integration of SCI survivors into the education system is associated with a range of characteristics which

include demographic variables (sex, gender and age), injury related factors, (including age at injury, functional status and period since injury) education history (pre-injury goals and aspirations), psychosocial issues (transportation, motivation level, life satisfaction, locus of control, social support and physical health). Additionally, negative emotional responses to SCI (such as depression and anxiety) and the severity and impact of disability were found to adversely affect survivor adjustment. Failure to resume studies for pre-injury school going survivors is detrimental to their post injury independence, well-being and personal development success rates. In fact, the study established that the resumption of studies may be the most documented adjustment factor for SCI survivors. The study established that as survivors move in transition from remaining at home to going back to school, adjustment increases. The adjustment trends observed tended to indicate that those SCI survivors who shifted from pre- injury 'learning' status to post injury 'no learning had the rate of adjustment lowered, while those who moved from pre-injury 'learning' to postinjury 'learning' made credible adjustment.

Low socio-economic status too was found to be risk factor for SCI survivor post trauma adjustment; 76% the survivors who came from socio-economically disadvantaged backgrounds recording higher chronic and emotional distress than the others. The socioeconomic status was the most commonly cited vulnerability, associated with reintegration into the education system among the SCI survivors. The social and demographic disparities noted among the survivors include the socioeconomic status, which was assessed by the distinctive difference in income, educational attainment and occupational status. This factor was consistently associated with differences in SCI post traumatic emotional adjustment.

The study findings imply significant disparities in the psychosocial outcomes owing to differences in individual pre-injury background and socio-demographic characteristics. This was observed to be more prevalent among the vulnerable socio-economically disadvantaged SCI survivors, among them those who live in informal settlements. Survivors in this group reported disparate access to medical and rehabilitative services as well as basic resources, resulting in poor post trauma adjustment.

REFERENCES

1. Abraham (1943)
2. Anderson, C. J. (2009). Anxiety and depression in children and adolescents with spinal cord injuries.
3. *Dev.med child Neurol* 826.832.
4. Barker, (2009)
5. Cathey Hurt (2008)
6. Crowell, S. (2009). *Symptoms of Depressive Disorder*. Eaglewood Cliffs: Prentice-Hall.
7. Fabes, R.O. (2012). *Practical Counselling*. Chicago: Thomas More Press.
8. Franceschini, M. (2003). Longitudinal outcome 6 years after spinal cord injury. *Spinal Cord*, 41, 280-5.
9. Gosney, S. M. (2011). *Post- Traumatic Response*. New York: Demos Books.
10. Groot, C. O. (2012). *Psychotherapy and Stress Management*. London: Addison Wesley.
11. Holtz, A. (2010). *Spinal Cord Injury*. New York: Oxford University press.
12. Katharine, S. (2012). *Chronic Illness and Emotional Health*. New York: McGraw – Hill Publishing Co.
13. K.P.O/ WHO. (2009). *Country Report - Kenya Reporting period*. January 2004- December 2006. Nairobi: Republic of Kenya.
14. Kruse (2006)
15. Krause, W. J. (2008). *Emotional Adjustment and Spinal Cord Injury*. London: Sage.
16. Tuckman (1978)
17. United Nations (2010)
18. UNESCO (2010)
19. UNICEF. (2006). *The UN Secretary General's Study on School Dropout Rates*. Nairobi: GOK.
20. UNICEF (2011)
21. United State Synovate (2006)
22. Warren (2004)
23. WHO (2001)
24. WHO (2007)
25. WHO (2013)