

# Well-Being Programme for Caregivers of Persons with Spinal Cord Injury: A Feasibility Study

Pallerla Srikanth<sup>1</sup>, Shanivaram Reddy K.<sup>1\*</sup>, BP Nirmala<sup>1</sup>, Janardhana N.<sup>1</sup>,  
Anupam Gupta<sup>2</sup>

<sup>1</sup>Department of Psychiatric Social Work, NIMHANS  
<sup>2</sup>Department of Neurological Rehabilitation, NIMHANS

## ABSTRACT

**Background:** SCI is a high-cost chronic disability, and it is a life-changing experience for family members and societies. For families, the unpredictable nature of the injury leads some of the members into an 'unexpected career' as family caregivers, the caregiver's have to put enormous efforts, to provide continuous full-time caregiving for the recovery of Person with Spinal cord injury, which will affect the caregiver's physical and mental health. The current study aims to develop and test the feasibility of a well-being programme for caregivers of persons with spinal cord injury.

**Methods/Design:** The current study adopts a Quasi-experimental study design, which have three phases; the first phase is to explore the needs of the caregivers by conducting in-depth interviews with different stakeholders. The second phase is to develop a well-being programme, and checking the feasibility of the programme is the third phase by recruiting 24 caregivers. Qualitative data will be analyzed using thematic analysis, whereas quantitative data will be analyzed using appropriate parametric or non- parametric tests upon confirming normality of data distribution.

**Discussion:** This study would help us to understand the psycho-social issues and unique needs of the caregivers at different time periods. It also gives information about psycho-social interventions and outcome measures for the well-being of the caregivers.

**Keywords:** Spinal cord injury, caregivers, well-being, psycho-social

## 1. Background

### 1.1 Introduction

Spinal cord injury (SCI) is a catastrophic event that may occur suddenly and unexpectedly. In addition, SCI may cause permanent disability and decreased life expectancy (Polinder et al., 2007). The incidence rates of SCI in developed countries range from 13.1 to 163.4 per million people (Pickett et al., 2006) (O'Connor & Murray, 2006). The incidence rates of SCI in developing countries vary from 13.0 to 220.0 per million people (Löfvenmark et al., 2015; Sabre et al., 2015). In India, approximately 1.5 million people live with SCI. Approximate 20,000 new cases of SCI are added every year, and 60-70% of them are illiterate, poor villagers.

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\* Correspondence to Dr Shanivaram Reddy K, Assistant Professor, Department of Psychiatric Social Work, NIMHANS, Bengaluru, 560029, India. Email: shanivaramreddyk@gmail.com

The majority of them were males in the age group of 16-30 years, signifying higher incidence in young (Fehlings et al., 2014).

The main cause of SCI in developed countries used to be MVAs (Motor Vehicle Accident's), however, recent research conducted in underdeveloped countries have proved that Fall from height is the most common cause (Sabre et al., 2012). Furthermore, it is a life-changing experience for the person who suffers from it and his/her parents, spouse, children, and siblings (Lude et al., 2014). Functional restrictions caused by physical problems can reduce quality of life for SCI patients and their families (Nikbakht et al., 2019). When a family member becomes affected by SCI, the rest of the family members will do their best to improve the conditions. The methods of adaptation vary from family to family (Simpson & Jone, 2012). Following spinal cord injury (SCI), spouses and other family members are often called upon to undertake the caregiving role (Post et al., 2005). Changes like the relationship (e.g., role change from spouse to caregiver) between the individuals with SCI and their families can challenge the family physically, psychologically, and socially (Middleton et al., 2014). Comparable to the individuals with SCI, the family care-givers are often required to reconstruct their lives, as well start an "unexpected career" to provide support with activities of daily living (ADLs), personal care, and emotional support to their family member with a disability (Archbold et al., 1990; Dickson et al., 2010). The stress associated with assuming the caregiving role (Chan et al., 2000) can influence the adjustment of individuals with SCI and their families (DeSanto, 2009) and (Cleveland, 1980).

Determined that tasks associated with caring for an individual with SCI were often unevenly distributed amongst family members, resulting in increased stress in communication, family unity, family power structure, and interpersonal relationships. In a recent descriptive cross-sectional study assessing the relationship between sociodemographic factors and the level of burden experienced among caregivers of individuals with SCI, it was reported that parents experienced significantly more burden undertaking the caregiver role than spousal caregivers (Khazaeipour et al., 2017). Emerging literature on dyadic coping between care-givers and care recipients provides insight into how couples manage health, relational, and psychosocial issues (Bodenmann et al., 2005). Although these studies offer valuable insight into the nature of caregiving relationships, the extent to which these findings can be generalized to individuals with SCI and their family caregivers is unknown indeed. Providing care to individuals with SCI is distinct from other illnesses and injuries due to the unique challenges of providing care related to the complications associated with SCI (e.g., bladder and bowel problems, and pressure injury management (Nogueira et al., 2012) and the longer duration of their caregiving period (Schulz et al., 2009).

There is limited research on how individuals with SCI and their family caregivers adapt to their new lives post-injury or how dyadic coping strategies are used to maintain relationships. Furthermore, when an individual is younger (i.e., young adult) and not married, the role of care-giving most often falls to the parents. Yet, there is a paucity of published literature on parents as caregivers and the impact of SCI on the parent-child relationship. There is an increased need for qualitative research examining the care givers needs post injury. For families, the unpredictable nature of the injury leads some of the members into a 'unexpected career' as family caregivers (Dickson et al., 2010). As family caregivers usually do not have training for the caregiving tasks (e.g., bathing, dressing and feeding), strain, (Middleton et al., 2014) isolation, (Guilcher et al., 2012) burden, (Khazaeipour et al., 2017) poor leisure satisfaction, (Raj et al., 2006) reduced ability to become and remain employed (Ellenbogen et al., 2006) and marital disruption (Dickson et al., 2012).

## 1.2 Aim

The present study aimed to develop and test the feasibility of well-being programme for care givers of persons with spinal cord injury.

## 1.3 Objectives

The present study has two objectives, one is primary and another is secondary objective, which have mentioned in the below. The process of the whole study has mentioned in the below Table 1.

### *Primary:*

The primary objectives of the present study are

- To explore the psycho-social needs of caregivers.
- To develop a comprehensive well-being programme for caregivers.
- To test the feasibility of well-being programme in improving the family functioning, socio-occupational functioning, coping, well-being and in decreasing the care giver strain.

### *Secondary:*

- The secondary objective of this study is to develop a check list for the assessment.

**Table 1.** Objectives of each phase of the study.

S.no	Objective	Process
1.	To explore the psycho social needs of the caregiver's	Review of literature Semi structured interview schedule Qualitative assessment through In-depth direct interviews, telephonic interviews with caregiver's, Stakeholders
2.	To develop the check list	Development of check list
3.	To develop a comprehensive well-being programme for caregiver's	Development of well-being programme Validation by experts Pilot study
4.	To test the feasibility of well-being programme for caregiver's	To collect the Socio demographic data for the caregiver's To collect the illness data for the PwSCI Applying scales for the caregiver's & Case studies Quantitative & qualitative evaluation

## 1.4 Hypotheses

H1: Well-being programme improves coping and well-being of the caregivers.

H2: Well-being programme improves family functioning and socio-occupational functioning of the caregivers.

H3: Well-being programme decreases the care giver strain.

## **2. Literature Review**

### **2.1 Different perspectives in SCI needs**

Individuals with SCI and their families, as well as healthcare professionals must work together to effectively meet the diverse post SCI needs (Glass et al., 1991) For rehabilitation professionals, understanding the interplay of different factors influencing support mechanisms to assist the transition to home and community after discharge can facilitate social reintegration of the individual with SCI (Kroll et al., 2008). Compared with family caregivers of different neurological conditions, family caregivers of individuals with SCI have experienced more frequent physical distress and present increased odds of coronary heart disease and obesity (Lavela et al., 2015). Thus, their experience as family caregivers is crucial to understand the needs of individuals with SCI, as they progressively become experts by experience while providing care, supporting and addressing the needs of the care recipient with SCI.

Family caregivers are an essential resource in treating individuals with SCI considering that the quality of the care they provide matches or exceeds the quality of professional care (Smith et al., 2016). However, unmet caregiver needs may prevent optimal care and negatively affect the health of both the care recipients and their own. From a clinical perspective, understanding the needs of individuals with SCI, knowing the person and working with the family can be beneficial to guide their healthcare and improve outcomes (Stiens et al., 2013). As unmet needs have a direct relationship with diminished quality of life (Noreau et al., 2014). It is mandatory to understand them and to find ways to meet them. Consequently, obtaining a comprehensive picture of needs by integrating the different perspectives of professionals, family caregivers and individuals with SCI is paramount.

### **2.2 Changing needs in the rehabilitation continuum**

The challenge is in understanding the evolution of these needs as they change over time. The literature on SCI needs indicates that in the first-year post discharge, the fulfilment of critical requirements (eg., housing and transportation) is below 60% (Beauregard et al., 2012) while the long-term care needed is higher than the care received for information and psychosocial care needs (Van et al., 2009). Furthermore, there are differences in needs between individuals with traumatic and non-traumatic SCI. Finally, fully addressing the needs of individuals with SCI must include evaluating and targeting the needs of family caregivers. Family caregivers of individuals with SCI report health information needs as the most critical and emotional support needs as those most often unmet (Meade et al., 2004). Unmet needs lead their family caregivers to invest more hours in their care (Smith et al., 2016).

### **2.3 Gaps in understanding met and unmet needs**

Previous studies have evaluated SCI needs separately at different points of the rehabilitation continuum (such as inpatient, outpatient and community) from the perspective of individuals with SCI, family caregivers and healthcare professionals. Furthermore, studies have mainly considered SCI needs from a health services perspective rather than from a patient-centred and care givers perspective that accounts for areas that influence needs outside of the health system. No previous studies have evaluated the variations in factors and synthesizing these needs together from a patient-centred and care givers perspective. With fragmented information, it remains difficult for patients, family caregivers, health professionals and researchers to understand the current gaps in SCI care and the most efficient ways to deliver care that are most likely to address unmet needs.

### **3. Theoretical Framework**

#### **3.1 Diathesis–stress model/ Dual-risk model**

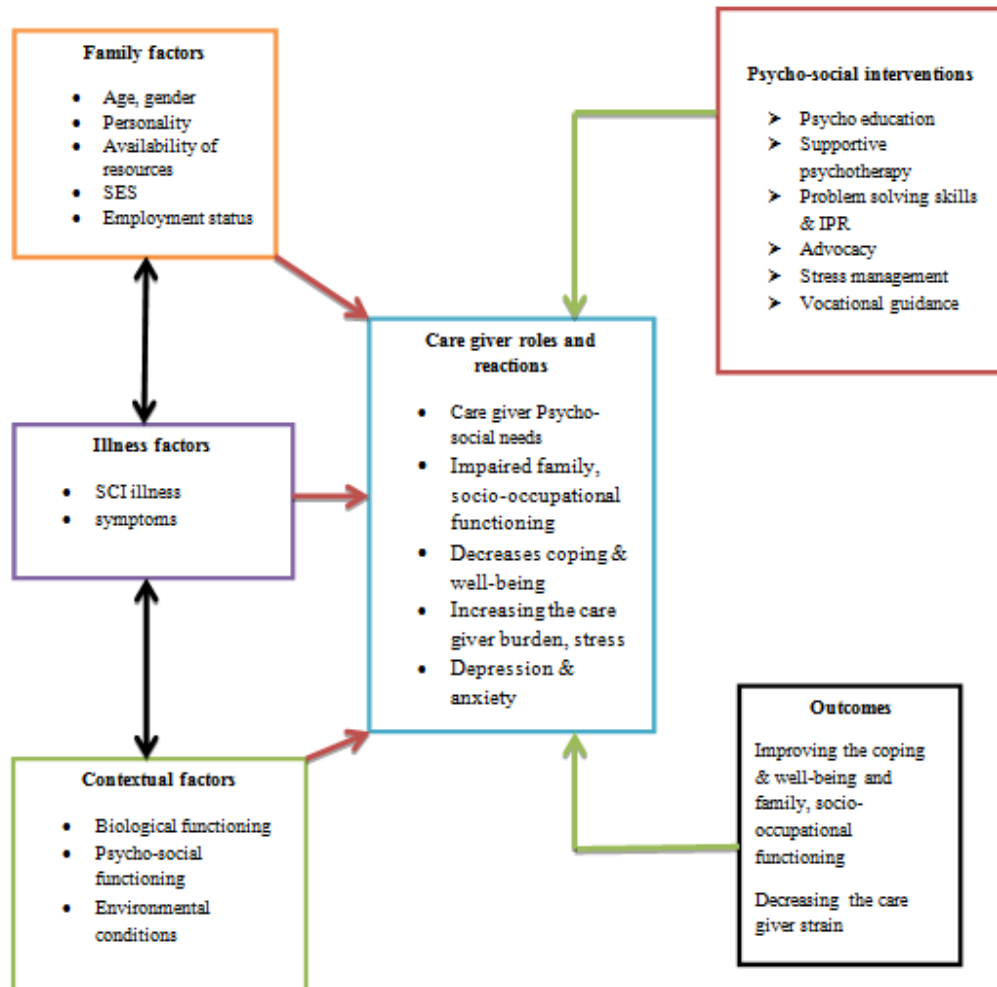
The diathesis–stress model is a psychological theory that attempts to explain a disorder due to an interaction between a predispositional vulnerability and a stress caused by life experiences. A diathesis can take the form of genetic, psychological, biological, or situational factors (Ingram et al., 2005). A large range of differences exists among individuals' vulnerabilities to developing a disorder (Ormel et al., 2013). An interaction between a predispositional vulnerability and a stress caused by life experiences explores how biological or genetic traits (diatheses) interact with environmental influences (stressors) to produce disorders such as depression, anxiety, or schizophrenia.

The diathesis, or predisposition, interacts with the individual's subsequent stress response. Stress is a life event or series of events that disrupts a person's psychological equilibrium and may catalyze the development of a disorder (Green et al., 2007). Thus, the diathesis–stress model explores how biological or genetic traits (diatheses) interact with environmental influences (stressors) to produce disorders such as depression and anxiety. Diathesis–stress models are often conceptualized as multi-causal developmental models, which propose that multiple risk factors over the course of development interact with stressors and protective factors contributing to normal development or psychopathology. Protective factors can counteract the effects of stressors and prevent or curb the effects of disorder, contributing to normal development or psychopathology (Masten et al., 2001).

#### **3.2 Conceptual map**

Multi-component approach will be used in understanding the concerns of caregivers of persons with SCI, which has illustrated in the Figure 1.

**Figure 1.** Multi-component approach explaining about the concerns of caregivers of persons with SCI.



*Note:* The roles and reactions of the caregivers of the PwSCI, can be well understood by the above multicomponent factors such as Illness factors, Contextual factors, Family factors, which will be addressed by the specific Psycho-Social Interventions, and the outcomes have illustrated in the above figure.

## 4. Methods/Design

### 4.1 Operational definitions

**Care giver:** Refers to person (Father, Mother, Sibling and Wife) who is providing primary care to the PWSCI and who will stay with the patient after the discharge of the patient for a period of minimum 6 months.

**Psychosocial needs:** It means the needs to deal with the distress arising due to the illness, such as, lack of knowledge about the illness, negative emotions, poor coping and problem-solving skills and disruption of family routine, leisure and financial strain, vocational aspects.

**Coping:** Refers to the behavioral and cognitive efforts made by individuals in attempting to deal with stressful situations, or means to invest one's conscious effort, to solve personal and interpersonal problems, in order to try to master, minimize or tolerate stress and conflict.

**Well-being:** Well-being is the experience of health, happiness, and prosperity. It includes good family functioning and socio occupational functioning, adequate coping strategies, problem solving skills and interpersonal relationship skills.

**Family functioning** of care givers includes impact on the daily activities, socio occupational and emotional aspects, impairment in the prescribed family roles, and the interactions and relationships within the family, particularly levels of conflict and cohesion, adaptability, and quality of communication.

**Social and occupational functioning:** An individual's interactions with their environment and the ability to fulfill their ability in work, social activities, and relationships with partners and family.

**Strain:** Caregiver strain is the perception of persistent problems and a feeling of decreased well-being that results from providing prolonged unexpected care. Caregiver strain is associated with burnout of caregivers and along with unmet care-recipient needs. Caregivers may be prone to depression, grief, fatigue, financial hardship, and changes in social relationships. They may also experience physical health problems.

**Disability:** Any restriction or lack of ability of an individual to perform an activity in the manner or within the range considered normal for a human being due to the person's neurological illness.

**Dropout:** The participants who consented for the study and completed baseline assessment but did not complete the post assessment or communicated their unwillingness to continue in the study have been considered as dropouts.

**Education:** Cares awareness about the diagnosis, symptoms, etiology, treatment, course, prognosis and management of the clinical condition.

## 4.2 Universe

All the primary care givers who have been providing the care to the person with spinal cord injury from the Department of Neurological Rehabilitation ward at NIMHANS, Bangalore.

## 4.3 Sample size calculation

Sample size is calculated using primary outcome change in Subjective well-being (SWBI) at 3 months after baseline. Two tailed alpha was set at 0.05 power at 80 percent. A standard effect size of 0.5 – a relevant effect for SWBI calculated using earlier findings from a recent trial which evaluates power / sample size. The sample size of 24 was calculated using G\*power software and considering the dropout rate.

## 4.4 Phase I:

### 4.4.1 Research design

It comprised of a Descriptive design wherein the psychosocial need assessment will be carried out.

### 4.4.2 Sampling method

Convenience sampling method will be utilized to recruit caregivers in phase – I.

## Need assessment for caregivers of persons with SCI

Phase – I will comprise of 2 parallel steps, as follows:

### **Step 1 Review of literature**

Review of literature will be done using PubMed, Google Scholar, PLOS, MEDLINE, EMBASE, Cochrane Library, Web of Science and SCOPUS, and ProQuest. Meta-analysis, systematic reviews, original articles, review articles, letter to editors published in the above-mentioned indices from January 2005 to December 2020 will be considered for review.

The focus of the search will be:

- To identify needs of the caregivers of persons with SCI.
- To identify various evidence-based psychosocial interventions for caregivers of persons with SCI.

### **Step 2 Assessment of caregiver needs**

From the literature review, semi-structured interview guide will be prepared. The guide will be used to conduct qualitative in-depth direct interviews and telephonic counseling using technological tools with caregivers until data saturation is achieved. For selection of caregivers for the in-depth interviews the caregivers must fulfil the following inclusion and exclusion criteria. All persons with SCI care givers accessing in-patient and out-patient services at Department of Neuro Rehabilitation ward tentatively between October – December 2020. Those who satisfy the both the inclusion criteria as mentioned below will be recruited for in-depth direct interviews and telephonic counselling.

#### **Inclusion Criteria:**

- Those aged 18 years above
- The caregiver must be able to converse in at least one of the languages: English, Kannada, Telugu and Hindi.
- Those who are willing to give consent to participate in the study.

#### **Exclusion Criteria:**

- The caregivers of having severe psychiatric or neurological disorders.
- The primary care giver who is involved in the care of another family member suffering from psychiatric or neurological condition.

#### **Criteria for the NGO'S**

NGO's working for the Spinal cord injury patients and their care givers will be taken as inclusion criteria.

#### **Professionals**

The Neuro Physicians, Occupational therapists Physiotherapists, Medical and Psychiatric social workers, clinical psychologists and other professionals who are working in the same field.

#### **4.4.3 Tools for data collection**

The researcher will prepare a semi structured interview guide for the In-depth direct interviews and telephonic interviews using technological tools with caregivers of persons with SCI. Similar guide will be used with expert to understand the nature of psychosocial problems faced by caregivers of persons with SCI, model and strategies for intervention based on the cultural aspect, challenges, etc that needs to be addressed.



#### 4.4.4 Statistical analysis

The in-depth direct interviews and telephonic calls will be audio-taped using a smart phone recorder and will be translated and transcribed into word file by the researcher. The content will be imported into NVivo software.

The researcher will analyse the content using the method of thematic analysis (Braun & Clarke, 2006) to code and cluster the identify needs of the caregivers.

#### 4.5 Phase – II

The Phase – II will comprise of 2 parallel steps, as follows:

**Development of check list:** The check list will be developed to assess the psycho social needs and to assess the knowledge about the illness and related factors. After assessing the needs by the care giver and PWSCI, different stakeholders a checklist will be developed to include the items related to all the needs expressed by the care givers and other stakeholders to provide specific problem-oriented intervention.

**Step-1** Develop and test the feasibility of psycho social intervention programme for care givers of persons with spinal cord injury a feasibility study. The content for psycho social intervention programme will be developed based on the needs identified and literature search to contribute evidence-based psychosocial interventions. The draft of the intervention program will be modified and validated through consultation meeting with experts in the field including Neurosurgeon, Neuro Rehabilitation doctors, psychologist, and psychiatric social workers.

The tentative programme has mentioned in the below Table 2.

**Table 2.** *Tentative Well-being programme*

<b>Intervention</b>	<b>Nature of session</b>	<b>Duration</b>
Education about the illness	Group	2-3 sessions
Supportive psychotherapy	Individual	2-3 sessions
Problem solving skills & IPR	Group	2-3 sessions
Stress management	Group	2-3 sessions
Vocational guidance	Group	2-3 sessions
Advocacy	Group	2-3 sessions

**Step-2 Pilot Study:** The pilot study will be done to check the viability and feasibility of the quantitative scales for the main study.

#### 4.5.1 Statistical analysis

Based on the needs identified from the thematic analysis and from systematic review of literature, appropriate interventions will be developed in phase – II. The content of the intervention program and the check list will be given to experts for review and recommendation. Upon the experts' validation and recommendation, the program will be prepared for intervention phase after the pilot study.

## **4.6 Phase–III main study**

### **4.6.1 Research design**

Phase III: The research will be carried out using quasi-experimental study design with pre and post assessments without control group. The study will be carried out among the caregivers of persons with SCI who accesses in-patient based care at NIMHANS for SCI. The participants who meet inclusion and exclusion criteria will be provided the intervention upon obtaining informed consent. The group will be followed for a period of 3 months post intervention through Out-patient based booster sessions or telephonic follow up.

The group will undergo pre-assessment at the beginning of intervention and post assessment will be carried out at two time points, at the time of discharge and at the time of first follow-up, which will occur three months post intervention.

### **4.6.2 Sampling method**

Phase – III of the study based on the population who meet inclusion and exclusion criteria between the time period of 6 months (Tentatively, October, 2020 – June 2021).

The main study will be carried out with the caregivers of person with SCI who access in-patient facility at Department of Neuro Rehabilitation ward, NIMHANS. Among them, those who meet the following inclusion and exclusion criteria will be recruited for the study.

#### **Inclusion Criteria**

- Those aged above 18 years.
- Those willing to give the informed consent.
- Caregiver must be able to converse in at least on the following languages: English, Kannada, Telugu and Hindi.
- Those who will be staying with the patient till the follow up assessment.

#### **Exclusion criteria**

- The caregivers of having severe psychiatric or neurological disorders.
- The primary care giver is involved in the care of another family member suffering from psychiatric or neurological conditions.

Informed consent will be obtained from those caregivers who meet the inclusion and exclusion criteria. Pre-test will be done face-to-face using the traditional paper-pencil method. Their time of convenience and choice of communication will be obtained from the caregivers. The follow up assessment can be done face-to-face if met at the OPD or telephonic follow up appointment as per convenience of the caregivers. Care givers will be informed over the phone about the follow up assessment and inform to them that the same care giver can come to for the follow up but the care giver can make the final decision about the same. Five case studies will be carried out through the in-depth interviews during this phase.

### **4.6.3 Tools for data collection**

**Socio-demographic interview schedule:** The researcher will prepare a detailed psychosocial interview schedule. The schedule will collect information on socio-demographic details, clinical characteristics, and psychosocial problems of informal caregivers of persons with SCI. The schedule will be developed, face and content validated by experts before use in the main study.

**Hamilton Depression Rating Scale (HDRS) (Hamilton, 1960):** The HDRS (also known as the Ham-D) is the most widely used clinician-administered depression assessment scale. The original version contains 17 items (HDRS17) pertaining to symptoms of depression experienced over the past week. Method for scoring varies by version. For the HDRS17, a score of 0–7 is generally accepted to be within the normal range (or in clinical remission), while a score of 20 or higher (indicating at least moderate severity) is usually required for entry into a clinical trial.

**Hamilton Anxiety Rating Scale (HARS) (Hamilton, 1959):** The scale was developed in 1959 by Dr. M. Hamilton. The HAM-A probes 14 parameters and takes 15-20 minutes to complete the interview and score the results. An experienced clinician administers it. The scale has a total of 14 items 7 for psychic anxiety (mental agitation and psychological distress) & 7 for somatic anxiety. The scale has a high internal consistency (coefficient alpha) (0.92) and a good test-retest reliability of 0.96(3).

**WHO Disability Assessment Schedule (WHODAS) (World health organization, 2010):** Purpose People with mental illnesses often suffer disability that can range from relatively mild to severe. This instrument was designed to assess disability without regard to diagnosis. Description The WHODASII is a self-report measure that is one of a battery of measures developed by World Health Organization (WHO) teams. This scale has 36 items responded to with 32 questions. They are based on four International Classification of Impairment, Disability, and Handicap (ICIDH-2) dimensions: Impairments in Body Functions and Structure, Activity Limitations, Participation Restrictions, and Environmental Factors.

**General Functioning Family Assessment Device (GF-FAD) (Epstein, 1983):** The GF-FAD is a measure of overall satisfaction or distress with general family functioning which has 12 items that measure feelings, decision making process and supporting aspects within the family members. The FAD is among the most widely used assessment devices in research on family functioning, has good test-retest reliability and concurrent reliability, and multiple studies have found that it is able to discriminate between clinical samples and control samples (Staccini et al., 2015).

**Brief COPE Scale (Carver, 1997):** The Brief COPE (Coping Orientation to Problems Experienced) is a 28-item multidimensional measure of strategies used for coping or regulating cognitions in response to stressors. This abbreviated inventory (based on the complete 60-item COPE Inventory) is comprised of items that assess the frequency with which a person uses different coping strategies (e.g., “I’ve been turning to work or other activities to take my mind off things,” “I’ve been making fun of the situation,” “I’ve been criticizing myself”) rated on a scale from 1, I haven't been doing this at all, to 4, I've been doing this a lot.

**Subjective Well-Being Inventory (Sell, 1992):** Subjective Well-Being Inventory developed by (Nagpal & Sell, 1992) is a self-report questionnaire consisting of 40 items designed to measure an individual ‘s mental status regarding overall feeling about life. The inventory gauges eleven factorial dimensions: positive affect, Expectation, Achievement congruence, confidence in coping, Transcendence, Family group support, Social support, Primary group concern, and inadequate mental mastery Perceived ill-health, Deficiency in social contacts and General wellbeing negative affect. The scale has been found to have high inter-rater, inter-scoring, and test-retest reliability.

**The Social and Occupational Functioning Assessment Scale (Morosini et al., 2000):** The SOFAS is a new scale that differs from the global assessment of functioning (GAF) scale in that it focuses exclusively on the individual's level of social and occupational functioning. The SOFAS is usually used to rate the functioning for the current period (i.e., the level of functioning at the time of the evaluation). The SOFAS may also use to rate functioning for other time periods. For example, for some purpose it may be useful to evaluate functioning for the past year (i.e., the highest level of functioning for at least a few months during the past year).

**The Modified Caregiver Strain Index (MCSI) (Wilson et al., 1999):** The Modified Caregiver Strain Index (MCSI) is an easy-to-use tool that can quickly screen for caregiver strain in long-term caregivers. The tool has 13 questions that measure strain related to care provision. There is at least one item for each of the following major domains: Financial, Physical, Psychological, Social, and Personal. This instrument can be used to assess individuals of any age who have assumed the care giving role for an older adult.

#### 4.6.4 Statistical analysis

At the beginning of the study, pre-test will be done with outcome measures. The post-test assessment will be carried out at discharge and three months after the intervention during follow up. The outcome variables will be entered in MS Excel and imported into R-Software for statistical analysis. The case studies will be analyzed through qualitative methods. Upon confirming normality of data distribution, appropriate parametric or non- parametric test will be used, as mentioned in the Table 3.

**Table 3.** *Statistical analysis for Phase-III.*

Hypotheses	Statistical Test
H1 : well-being programme improves coping and well-being of the CGPWSCI.	Friedman's Test or RMANOVA
H2 : well-being programme improves family functioning and social occupational functioning of the CGPWSCI.	Friedman's Test or RMANOVA
H3 : well-being programme decreases caregiver strain among CGPWSCI	Friedman's Test or RMANOVA

## 6. Ethical Considerations

Institute Ethical Committee clearance was sought for the current study, (No. NIMH/DO/BEH.Sc.Div./2020-21). Informed consent form will be obtained in writing from the PwSCI & care givers. The participants will be explained in detail about the nature of the study and the voluntary nature of participation. The participants will be administered scales for data collection only upon obtaining written informed consent. Anonymity and confidentiality of the participants will be maintained through the study. Permission to audio-record the qualitative data and store the data till end of research work will be obtained from the participants. The name or other identifiable socio-demographic details will not be published or shared with third party whatsoever. A clause on participants to maintain confidentiality of the other group members will be added in the informed consent form. The patient will be given a choice to not answer a question or take back the consent at any point of time of the interview or intervention without any explanation. Appropriate referrals to individual psychotherapy or

pharmacotherapy will be recommended if the need is felt. Researcher will remind the participants about the follow up but shouldn't ask them to come for the follow up to collect the data.

## Declarations

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**Competing interests:** The authors declare that they have no conflict of interest.

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