

**A GROUP RESILIENCE-PROMOTING PROGRAMME (GRPP) FOR
INDIVIDUALS WHOSE PARTNERS HAVE ACQUIRED A SPINAL CORD
INJURY**

by

YOLINDA STEYN

UNIV DIPL (SOCIAL WORK), MA (SOCIAL WORK)

VAAL TRIANGLE CAMPUS

NORTH-WEST UNIVERSITY

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Promoter: Dr A Fouché

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Our Story

(2003 – current)

THIS POEM IS DEDICATED TO
Johan & Lesar Steyn
AND
Every SCIPP in South Africa

*Within a split-second-change
Broken bodies everywhere – fear and pain
Slowly reality dawns – life goes on
The known normal is forever gone*

*Family and friends rally round
Pray for us without a sound
Bodies heal [mine and my son's]
But Daddy's back is forever gone
A Paraplegic he will stay
A wheelchair and constant challenges will be the way*

*Choices to be made – the future seems bleak
Where will I go for the help I seek?
I will not despair and loose hope
But how are we going to cope?*

*Out of the chaos comes the call
God has given you a gift to help us all
Scientific knowledge – but this is not enough
A soul with experience, compassion and love
You will help and answer our desperate cry
Help us to understand the why?*

*Thank you Hubby [Daddy] for the choices you made
For the strength to carry on, and being brave
God comforted us in this season
To grow and find peace beyond all reason*

*In triumph we now live
Our family a unit with a lot to give
The challenges of life we face
Within Gods mercy and grace*

*by Yolinda Steyn
[POET: Issie Collatz]
December 2015*



PREFACE AND DECLARATION

The article format was chosen for the current study. The researcher, Yolinda Steyn, conducted the research and wrote the manuscripts. Dr Ansie Fouché acted as promoter. Three manuscripts were written and will be submitted for publication in the following journals:

MANUSCRIPT 1: Journal of Psychology in Africa

MANUSCRIPT 2: Social Work/Maatskaplike Werk

MANUSCRIPT 3: Tydskrif vir Geesteswetenskappe/Journal of Humanities

I declare that **A GROUP RESILIENCE-PROMOTING PROGRAMME (GRPP) FOR INDIVIDUALS WHOSE PARTNERS HAVE ACQUIRED A SPINAL CORD INJURY** is my own work and that all the sources that I have used or quoted are indicated and acknowledged by means of complete references.


Yolinda Steyn (Student number: 23085568)

December 2015



26 November 2015

I, Ms Cecilia van der Walt, hereby confirm that I took care of the editing of the PhD of Ms Yolinda Steyn titled *A Group Resilience-Promoting Programme (GRPP) for Individuals whose Partners have acquired a Spinal Cord Injury*.



MS CECILIA VAN DER WALT

BA (*Cum Laude*)

HOD (*Cum Laude*),

Plus Language editing and translation at Honours level (*Cum Laude*),

Plus Accreditation with SATI for Afrikaans and translation

Registration number with SATI: 1000228

Email address: ceciliavdw@lantic.net

Mobile: 072 616 4943

Fax: 086 578 1425

ABSTRACT

Spinal cord injury (SCI) is an acquired physical disability through traumatic injuries such as car accidents and shooting incidents, and non-traumatic injury such as a tumour on the spinal cord, amongst others. Unlike other parts of the body, the spinal cord does not have the ability to repair itself if it is damaged. Consequently, a person who has acquired an SCI will have a physical disability and will be either a paraplegic – paralysis of the lower part of the body, including the legs, or a quadriplegic, which is paralysis of all four limbs. Acquiring a spinal cord injury (SCI) has devastating long-term negative outcomes for the injured person as well as his/her cohabiting partner on a physical, psychological, psychosocial and socio-economical level. Exposure to such prolonged adversity and resulting negative outcomes calls for resilience, namely the ability to positively adapt despite the adversity being exposed to. Not all individuals have the natural ability to “bounce back”, and consequently resilience promotion is imperative. In South Africa, the focus of service delivery in rehabilitation centres is mainly centred on the injured person and consequently the well-being of the spinal cord injured person’s partner (SCIPP) is neglected. Little information is available on resilience-promoting programmes for SCIPPs; thus the main aim of this study was to design and develop a group resilience-promoting programme (GRPP) for SCIPPs.

The researcher mainly followed a qualitative research approach and included a small quantitative component. In the context of applied research, an intervention research model comprising six phases was employed. Phase 1, Problem analysis and project planning, was reported on in section A. Manuscript 1 reports on phase 2 (information gathering and synthesis), and consists of a qualitative research synthesis, and mainly aimed at organizing and synthesizing previous research on resilience-promoting processes in order to inform

the design and development of a group resilience-promoting programme (GRPP) for SCIPPs. After a systematic review and quality appraisal a total of 74 papers were selected to be quality appraised after abstracts and titles were assessed for relevance. Twenty-one studies were included and synthesized where after an outline for the content of a GRPP for SCIPPs was formulated. Conclusions and recommendations highlight that the formulated GRPP for SCIPPs needs to be further developed into an intervention that could be implemented with SCIPPs. As such, the researcher therefore proceeded with the study (see manuscript 2), aiming in developing small-group programme content and activities (using knowledge gathered from pre-existing interventions; resilience literature; consultations with experts; people living with spinal cord injury (SCI) and personal experience) to promote resilience in SCIPPs. By means of purposive sampling six advisory panel members from a diverse background were interviewed before and after the pilot study with two SCIPPs and one observer to contribute towards the further development of the GRPP for SCIPPs. A six-session GRPP for SCIPPs was formulated, including the following: (1) Information on SCI and resilience; (2) Help SCIPPs understand that their reactions to/emotions regarding these huge changes are normal; (3) Caretaking and support; (4) My dual role; (5) Own caretaking by SCIPPs; and (6) Termination and way forward. The newly developed GRPP for SCIPPs however had to be formally evaluated. Recommendations were made by professionals in the field that the GRPP for SCIPPs should first be subjected to peer review prior to implementing it with the target population. Therefore in manuscript 3 (reporting on phase 5 – evaluation) the evaluation purpose was to subject the GRPP for SCIPPs to peer review by means of an empirical study with professional role-players (social workers and psychologists) in the field of spinal cord injury, prior to exhibiting it to the target population. The six group sessions were presented to professional role-players (n=12) working within the field of

SCI during two 2-day workshops, whereby they were requested to evaluate the content and procedural elements of the GRPP for SCIPPs mainly by means of qualitative research, with a small numerical (quantitative) component. Thematic content analysis and basic descriptive statistics were employed. Overall positive feedback regarding the newly developed intervention was received, with suggested adjustments that needed to be made to the GRPP for SCIPPs prior to formal evaluation with the target group. The GRPP for SCIPPs will further be subjected to expert review in other provinces in South Africa, as the current participants were all from Gauteng. Furthermore, postgraduate students will be recruited to test the programme with the target-population in South Africa for possible further improvement and suggestions, as well as possible expansion to adjust this intervention to meet the needs of male SCIPPs; SCIPs themselves; children of a parent/s living with SCI; and also for post-injury cohabiting relationships, as this intervention might be a starting point for above-mentioned research-opportunities.

Keywords: Spinal cord, spinal cord injury (SCI), intervention research, social group-work, process-focused approach, a resilience-based framework, six resilience protective processes, social ecological conceptualisation of resilience, traumatic SCI, non-traumatic SCI, spinal cord rehabilitation, couple, spinal cord injured persons' partner (SCIPP), spinal cord injured person (SCIP), partner, cohabiting partner, qualitative research, qualitative research synthesis, design and development, group resilience-promoting programme (GRPP), evaluability assessment.

OPSOMMING

Spinalekoord-besering (SKB) is 'n fisiese gestremdheid wat opgedoen is deur traumatiese beserings soos motorongelukke en skietvoorvalle, en nie-traumatiese beserings soos 'n tumor aan die spinale koord, onder andere. Anders as ander dele van die liggaam, beskik die spinale koord nie oor die vermoë om hom te herstel as dit beskadig is nie. Gevolglik sal 'n persoon wat 'n SKB opgedoen het fisiese gestremdheid daarvan oorhou en sal óf 'n parapleeg wees – verlamming van die laer dele van die liggaam, ingeslote die bene – óf 'n kwadripleeg, wat verlamming van al vier ledemate inhou. Die opdoen van 'n spinalekoord-besering (SKB) het verpletterende langtermyn- negatiewe uitkomst vir beide die beseerde persoon en sy/haar saamwoonmaat op fisiese, psigologiese, psigososiale en sosio-ekonomiese gebied. Blootstelling aan sodanige uitgerekte teëspoed en gevolglike negatiewe uitkomst vereis veerkrag, naamlik die vermoë om positief aan te pas ten spyte van die rampspoed waaraan die partye blootgestel word. Nie alle individue beskik oor die natuurlike vermoë om te herstel nie; dus is veerkragbevordering van die uiterste belang. In Suid-Afrika val die fokus van dienslewering in rehabilitasiesentra hoofsaaklik op die beseerde persoon; dit volg dan dat die welstand van die spinalekoord-beseerde persoon se maat (SKBPM) verwaarloos word. Min inligting is beskikbaar oor veerkragbevorderingsprogramme vir SKBPMs; gevolglik is die hoofdoel van hierdie studie om 'n groep- veerkragbevorderingsprogram te ontwerp en te ontwikkel.

Die navorser het hoofsaaklik 'n kwalitatiewe navorsingsbenadering gevolg wat 'n klein kwantitatiewe komponent ingesluit het. In die konteks van toegepaste navorsing is 'n intervensie-navorsingsmodel wat uit ses fases bestaan het, ingespan. In afdeling A is verslag gelewer oor Fase 1, Probleem-analise en projekbeplanning. Manuskrip 1 het verslag gelewer oor fase 2 (inligtingsinsameling en sintese) en bestaan uit 'n kwalitatiewe navorsingsintese, en was hoofsaaklik ingestel daarop om vorige navorsing oor

veerkragbevorderingsprosesse te orden en te sintetiseer om daardeur inligting te verstrek in belang van die ontwerp en ontwikkeling van 'n groep-veerkragbevorderingsprogram (GVBP) vir SKBPMs. Na 'n sistematiese oorsig en kwaliteitswaardebepalings is 74 voordragte in totaal geselekteer waarvan die gehalte bepaal is nadat voordragte en titels vir toepaslikheid geassesseer is. Een en twintig studies is ingesluit en gesintetiseer waarna die hooflyne vir die inhoud van 'n GVBP vir SKBPMs geformuleer is. Gevolgtrekkings en aanbevelings het beklemtoon dat die geformuleerde GVBP vir SKBPMs verder in 'n intervensie ontwikkel moet word wat met SKBPMs geïmplementeer kan word. As sodanig het die navorser dus voortgegaan met die studie (sien manuskrip 2), wat daarop gemik is om kleingroep-programinhoud en -aktiwiteite te ontwikkel (deur kennis wat uit reeds bestaande intervensies, veerkragliteratuur, konsultasies met kundiges, mense wat met spinalekoord-beserings belas is en uit persoonlike ondervinding, ingewin is, te benut) om daardeur veerkrag by GVBP te bevorder. Deur middel van doelbewuste steekproefneming is ses adviserende paneellede uit 'n diverse agtergrond voor en na die loodsstudie genooi, met twee SKBPMs en een waarnemer om tot verdere ontwikkeling van die GVBP vir SKBPMs by te dra. 'n GVBP vir SKBPMs bestaande uit ses sessies is geformuleer, en die volgende is daarby ingesluit: (1) Inligting oor SKB en veerkrag; (2) Help SKBPMs om te verstaan dat hulle reaksies op/emosies rakende hul geweldige groot veranderinge normaal is; (3) Versorging en ondersteuning; (4) My dubbele rol; (5) Eie versorging deur SKBPMs; en (6) Terminering en die weg vorentoe. Die nuut ontwikkelde GVBP vir SKBPMs moes egter formeel geëvalueer word. Aanbevelings is deur professionele persone op die gebied gemaak, naamlik dat die GVBP vir SKBPMs eers aan ewekniebeoordeling onderwerp moet word voordat dit met die teikenpopulasie geïmplementeer word. In manuskrip 3 (wat oor fase 5 verslag lewer – evaluering – was die evalueringsdoel om die GVBP vir SKBPMs aan ewekniebeoordeling te onderwerp deur middel van 'n empiriese studie met

professionele rolspelers (maatskaplike werkers en sielkundiges) op die gebied van spinalekoord-besering, voordat dit aan die teikenpopulasie voorgehou word. Die ses groepsessies is tydens twee 2-dag-werkswinkels vir professionele rolspelers (n=12) wat op die gebied van SCI werk, aangebied, waar hulle versoek is om die inhoud en prosedurele elemente van die GVBP vir SKBPMs te evalueer, hoofsaaklik by wyse van kwalitatiewe navorsing, met 'n klein numeriese (kwantitatiewe) komponent. Tematiese inhoudanalise en basiese beskrywende statistiek is ingespan. Oor die algemeen is positiewe terugvoer met betrekking tot die nuut ontwikkelde intervensie ontvang, met aanbevole aanpassings wat aan die GVBP vir SKBPMs aangebring moes word voordat dit formeel met die teikengroep geëvalueer word. Die GVBP vir SKBPMs sal verder aan vakkundige beoordeling in ander provinsies in Suid-Afrika onderwerp word, aangesien die huidige deelnemers almal uit Gauteng afkomstig was. Voorts sal nagraadse studente gewerf word om die program met die teikenpopulasie in Suid-Afrika te toets vir moontlik verdere verbeteringe en aanbevelings, asook moontlike uitbreiding om hierdie intervensie ook sodanig aan te pas dat dit in die behoeftes van die manlike SKBPMs sal voorsien; SKBPMs self; kinders van ouer/s wat 'n SKB opgedoen het; en ook vir na-besering saamleefverhoudings, aangesien hierdie intervensie 'n moontlike beginpunt vir bogenoemde navorsingsgeleentheid kan wees.

Sleutelwoorde: Spinale koord, spinalekoord-besering (SKB), intervensie-navorsing, maatskaplike groepwerk, 'n proses-gefokusde benadering, 'n veerkraggebaseerde raamwerk, ses veerkrag-beskermende prosesse, sosio-ekologiese konseptualisering van veerkragtigheid, traumatiese SKB, nie-traumatiese SKB, spinalekoord-rehabilitasie, paartjie, spinale koord beseerde persoon se maat, saamwoon-maat, kwalitatiewe navorsing, kwalitatiewe navorsingsintese, ontwerp en ontwikkeling, groepveerkragbevorderingsprogram (GVBP), evalueringsassessering.

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