A Longitudinal View of Emotional Vitality in Caregivers

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DEDICATIONS

In dedication to my husband David Barbic and children Kisely and Carter

Thank you for being my Sherpas on this unbelievable journey....Kia Ora!

In memory of Matthew McCormick

Thank you for teaching me how to keep fire burning while walking in the rain.
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<th>Meaning</th>
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<tbody>
<tr>
<td>AIC</td>
<td>Akaike’s Information Criterion</td>
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<tr>
<td>BIC</td>
<td>Bayesian Information Criterion</td>
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<tr>
<td>CES-D</td>
<td>Center for Epidemiologic Scale for Depression</td>
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<tr>
<td>CG-QOL</td>
<td>Caregiver Quality of Life</td>
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<td>CI</td>
<td>Confidence Interval</td>
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<tr>
<td>CIS</td>
<td>Caregiver Impact Scale</td>
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<tr>
<td>DIF</td>
<td>Differential Item Functioning</td>
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<td>EV</td>
<td>Emotional Vitality</td>
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<tr>
<td>GBTM</td>
<td>Group Based Trajectory Modeling</td>
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<tr>
<td>GDS</td>
<td>Geriatric Depression Scale</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability, and Health</td>
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<tr>
<td>ICC</td>
<td>Item characteristic curve</td>
</tr>
<tr>
<td>MHI</td>
<td>Mental Health Index</td>
</tr>
<tr>
<td>N</td>
<td>Number</td>
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<tr>
<td>NS</td>
<td>Non-significant</td>
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<tr>
<td>OR</td>
<td>Odds Ratio</td>
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<tr>
<td>P-EVM</td>
<td>Prototype Emotional Vitality Measure</td>
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<tr>
<td>PFI</td>
<td>Physical Function Index</td>
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<tr>
<td>PSI</td>
<td>Person Separation Index</td>
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<tr>
<td>RMT</td>
<td>Rasch Measurement Theory</td>
</tr>
<tr>
<td>RUMM</td>
<td>Rasch Unidimensional Measurement Model</td>
</tr>
<tr>
<td>SAS</td>
<td>Statistical Analysis Software</td>
</tr>
<tr>
<td>SD</td>
<td>Standard Deviation</td>
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<tr>
<td>SE</td>
<td>Standard Error</td>
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<tr>
<td>SIS</td>
<td>Stroke Impact Scale</td>
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<tr>
<td>ssBIC</td>
<td>Sample Size Bayesian Information Criterion</td>
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ABSTRACT

The management of post-stroke recovery has changed considerably in recent decades, with approximately 80% of individuals returning home and rehabilitating in the community made possible because of the support of family members to provide care to meet their daily needs. Stroke caregivers are required to quickly learn rehabilitation and medical management techniques, while adjusting to changes in their relationships with the person who experienced the stroke. Unsurprisingly, stroke caregivers report high levels of stress and burden related to the deterioration of their own health status, social relationships, quality of life, and poor rehabilitation outcomes for the stroke survivor.

Emotional vitality is an emerging concept characterized by a sense of positive energy and effective emotional regulation in order to remain interested, engaged and productive in life. While emotional vitality may serve as a critical buffer against caregiver strain, very little is known about what enables some caregivers to thrive and be emotionally vital in this role, and others to burnout. This thesis was designed to contribute to the understanding of the caregiving experience by taking a longitudinal view of emotional vitality.

The first three studies contributed to the development of a conceptual and measurement framework for caregiver emotional vitality that included five domains: i) physical health and well-being; ii) support and recognition from others; iii) engagement in meaningful activity; iv) mood regulation; and v) a sense of control/mastery of new skills. The fourth study contributed evidence towards
the measurement properties of a set of 19 items that reflect the emotional vitality construct as it pertains to caregivers of stroke survivors.

A final study was aimed at providing preliminary evidence for how this measure of emotional vitality behaved longitudinally. Specifically, the objectives were to (i) estimate the extent to which caregiver emotional vitality changes in the first caregiving year; and (ii) estimate the extent to which caregiver characteristics and the functional profile of the care recipient impacts a caregiver’s emotional vitality in the first year. From a sample of 409 caregivers (mean age 59 years, SD 15), five trajectories of emotional vitality were identified. Most caregivers (4 trajectories representing 78% of participants) displayed low levels of emotional vitality that remained persistently low over time. The concordance between caregiver baseline levels of mastery and emotional vitality was fair (kappa=0.45).

In summary, emotional vitality in caregivers was on average very low in the first caregiving year. Mastery may be a component cause of emotional vitality, lending support to the importance of the need for health professionals to incorporate assessment of caregiver emotional vitality and mastery throughout the caregiving experience.
Depuis les dernières décennies, la gestion de la guérison suite à un accident vasculaire cérébral (AVC) a considérablement évolué. Approximativement, 80% des gens retournent à la maison et font leur réhabilitation dans la communauté. Ceci est rendu possible grâce au soutien des membres de la famille qui leur procurent des soins pour rencontrer leurs besoins quotidiens. Les aidants naturels des personnes ayant eu un AVC doivent apprendre rapidement des techniques de réadaptation et de gestion des médicaments, tout en s'adaptant à des changements dans leur relation avec la personne ayant eu un AVC. Il n'est donc pas surprenant de voir chez ces aidants naturels un niveau de stress plus élevé. De plus, le fardeau lié à la détérioration de leur propre état de santé, de leurs relations sociales et de leur qualité de vie résulte souvent en de mauvais résultats de réhabilitation chez les survivants d'un AVC.

La vitalité émotionnelle est un concept émergent caractérisé par un sentiment d'énergie positive et une régulation des émotions efficace afin de rester intéressé, engagé et productif dans la vie. Alors que la vitalité émotionnelle peut servir de tampon contre la pression ressentie chez les aidants naturels, on en connait très peu sur ce qui permet à certains aidants naturels de réussir et être émotionnellement vital dans ce rôle et d’autres seront complètement épuisés. Le but de cette thèse est de contribuer à la compréhension de l’expérience des aidants naturels en prenant une vue longitudinale de la vitalité émotionnelle.
Les trois premières études ont contribué à l’élaboration d’un cadre conceptuel et de mesure pour la vitalité émotionnelle chez les aidants naturels. Ce cadre inclus cinq domaines : i) la santé et le bien-être physique ; ii) l’appui et la reconnaissance d’autrui ; iii) l’engagement dans des activités significatives ; iv) la régulation de l’humeur ; et v) le sentiment de contrôle/maîtrise de nouvelles compétences. La quatrième étude a contribué aux évidences des propriétés de mesure d’un ensemble de 19 items illustrant le concept de la vitalité émotionnelle en ce qui a trait aux aidants naturels des survivants d’un AVC.

Une dernière étude a utilisé cette mesure afin (i) d’estimer la mesure dans laquelle la vitalité émotionnelle chez les aidants naturels change dans la première année de soins; et (ii) d’estimer la mesure à laquelle les caractéristiques des aidants naturels ainsi que le profil fonctionnel du bénéficiaire des soins influencent la vitalité émotionnelle des aidants naturels dans la première année. À partir d’un échantillon de 409 aidants naturels (moyenne d’âge de 59 ans, SD=15), cinq trajectoires de vitalité émotionnelle ont été identifiées. La majorité des aidants naturels (quatre trajectoires représentant 78% des participants) a démontré un faible niveau de vitalité émotionnelle qui est demeuré bas au fil du temps. La concordance de départ entre le niveau de maîtrise et de vitalité émotionnelle chez les aidants naturels était bonne (kappa=0.45).

En résumé, la vitalité émotionnelle chez les aidants naturels était en moyenne très faible dans la première année de soins. La maîtrise peut être une partie constitutante de la vitalité émotionnelle. Ceci démontre l’importance et la nécessité que les professionnels de la santé intègrent dans leur évaluation la
vitalité émotionnelle et la maîtrise des aidants naturels, et ce, tout au long de l’expérience de soins.
PREFACE

This thesis presents work carried out to understand emotional vitality in caregivers of stroke survivors. Emotional vitality is an emerging concept that describes an individual’s overall sense of energy, positive well-being, personal mastery, and emotional regulation within the broader context of emotional function. While emotional vitality may serve as a critical buffer against the strain of caregiving, very little is known about what enables some caregivers to thrive and be emotionally vital in the caregiving role. Further, it is unclear how to best support this group to ensure that they can continue to meet the physical and emotional needs of the stroke survivor without incurring significant cost to their own health, quality of life, and emotional well-being. To address this gap in knowledge, the studies in this thesis are designed to contribute to the understanding of the caregiving experience by taking a longitudinal view of emotional vitality.

Thesis Organization and Overview

This is a manuscript thesis, a format allowed by the Faculty of Graduate Studies at McGill University. The advantage of this format is that the expected contributions to the clinical and research community are quickly transferrable; a disadvantage is that the thesis is at times repetitive.

The thesis consists of five studies, each designed to answer specific research questions aimed at contributing evidence towards emotional vitality as a construct of importance to be addressed in the field of rehabilitation. Each study is
presented as a separate manuscript. A single data set was used for the last three studies. As a result, some repetition exists between manuscripts in the description of study population and procedures. The manuscripts contain substantial detail with respect to both methodology and interpretation of findings; however for the purpose of publication, the detail has been reduced to comply with journal requirements.

A brief outline of the thesis is as follows. A short introduction provides a brief overview of the thesis topics, rationale, and global objective. Chapter 1 summarizes the scientific literature on the substantive and methodological topics covered in the thesis including the role of emotional vitality in supporting caregiving of stroke survivors and the role of modern psychometric methods as a means to capture the latent construct in this population. Given the following chapter is a scoping review of the literature on the topic of emotional vitality, Chapter 1 summarizes only briefly the topic of emotional vitality. In addition, the topic of Rasch Measurement Theory is talked about extensively in Chapters 4 and 5, so this topic also only briefly discussed in Chapter 1.

Chapter 2 consists of Manuscript 1, entitled ‘Emotional Vitality: A concept of importance for rehabilitation.’ This study outlines the scope and breadth of knowledge currently available regarding the definition and measurement of emotional vitality in persons with chronic health conditions and identifies the extent to which the International Classification of Functioning, Disability, and Health (ICF)\(^1\) model includes components relevant to this construct. Activities included: a scoping review of the literature and a Delphi
mapping exercise using ICF. The results of this study revealed that emotional vitality is a complex latent construct, potentially comprised of four components including: (i) physical energy and well-being, (ii) regulation of mood, (iii) mastery, and (iv) engagement and interest in life. Manuscript 1 is currently accepted for publication and the status of the paper is “in press”.

Chapter 3 consists of Manuscript 2, entitled ‘Emotional Vitality the caregiver perspective: a concept analysis.’ This study describes emotional vitality in the context of the caregiving experience and proposes a working model of emotional vitality for caregivers of stroke survivors. A secondary analysis of interviews with 30 community dwelling caregivers of stroke survivors was conducted. Caregivers were asked to describe changes in their health, relationships, social roles, financial situation, and mood after assuming the caregiving role. Transcripts were re-analyzed using a bottom up discourse approach that coded key words describing the impact of the caregiving experience on emotional vitality. Identified themes important to caregiver emotional vitality were: (i) physical health and well-being; (ii) support and recognition from others; (iii) engagement in meaningful activity; (iv) mood regulation; and (v) sense of control/mastery of new skills.

Chapter 4 consists of Manuscript 3, entitled ‘The role of Rasch analysis in concept exploration: the case for emotional vitality in caregivers’. In this study, Rasch analysis was used to explore the construct validity of the working theoretical model of emotional vitality for stroke caregivers that resulted from Manuscripts 1 and 2. Using a secondary dataset of 107 items answered by
caregivers of individuals with stroke over one year, Rasch analysis afforded an in-depth view of how these items could be mapped back to the working conceptual model of emotional vitality. Specifically, 23 of these items quantitatively represented the structure of the emotional vitality construct, fitting together uniformly to reflect a unidimensional concept covering the full statistical range of emotional vitality of caregivers of stroke survivors. However, using this statistically guided approach, global fit of the Rasch model was not achieved longitudinally, and all items did not meet the fit criteria of the Rasch model. The longitudinal comparison between item rank and participant ability showed that the items were stable across time and with little evidence of a response shift in the first year of caregiving. However, at the individual item level, the study revealed that items did not fully capture the construct of emotional vitality. Valuable information was gleamed about the ordering of response categories of each item, individual and item fit, as well as targeting of these items to the sample. Taken together with the results from Manuscripts 1 and 2, it was felt that there was enough evidence to further test this well-developed concept and its dimensions. In order to do so, future work was needed to develop a measurement strategy to capture emotional vitality and test the validity of the conceptualization in a caregiver population.

Chapter 5 consists of Manuscript 4, entitled ‘Emotional Vitality in caregivers of stroke survivors: application of Rasch Measurement Theory to support a measure’. This study used Rasch Measurement Theory to re-examine the data set used in Manuscript 3 to contribute evidence towards the measurement properties of a set of items reflecting the emotional vitality latent construct as it
pertains to caregivers of stroke survivors. Items from the initial pool were selected based on \textit{a priori} hypotheses about item hierarchy and fit to the conceptual model. The results supported a prototype 19-item measure of emotional vitality (P-EVM) as an appropriate way of quantifying the construct for caregivers of individuals who have experienced a stroke.

Chapter 6 consists of Manuscript 5, entitled ‘Trajectories of emotional vitality of caregivers of stroke survivors in the first year of caregiving’. The overall aim of this study was to provide preliminary evidence for how the P-EVM behaved over time, contributing to the understanding of the stroke caregiving experience. The specific objectives were to estimate the extent to which (i) caregiver emotional vitality changes in the first caregiving year; and (ii) estimate the extent to which caregiver characteristics and the functional profile of stroke survivors impacts a caregiver’s emotional vitality in the first year. Group based trajectory modelling was used to identify caregiver and stroke survivor characteristics that were associated with caregiver emotional vitality across time.

To my knowledge, this was the first study to explore the factors that predict emotional vitality in the first year post-stroke. The study revealed distinct patterns that have not yet been discussed in stroke caregiver literature. Most caregivers displayed persistent low levels of emotional vitality in the first year of caregiving, while approximately one third displayed emotional vitality patterns that decreased slightly over the first year. Caregiver level of mastery one month post stroke was found to be an important component cause of emotional vitality.
Chapter 7 consists of the *Summary of Results, Discussion and Conclusion*, in which the findings are synthesized across studies and discussed in relation to previous research, occupational therapy practice, and the implications for future work. The methodological limitations and strengths of the PhD project are discussed.

Tables and figures are presented at the end of each manuscript. Page numbers of all tables and figures are listed in the indices of tables and figures following the table of contents. A table of abbreviations is located after the index of figures. References for all chapters, including the manuscripts, can be found in a combined numerically ordered reference list following chapter 7. Appendix A lists the references in alphabetical order.

**Contribution of Co-Authors**

For the all five manuscripts (*Chapters 2-6*), the candidate conceptualized the research questions, performed all statistical analyses, and wrote the manuscripts with feedback provided from both supervisors, Dr. Nancy Mayo and Dr. Susan Bartlett. The data for *Manuscripts 3, 4, and 5* came from a previous study that evaluated health related quality of life of individuals with stroke and their caregivers. The candidate used this data for a concept analysis, development of a prototype measure, and to measure emotional vitality in caregivers in the first year post-stroke.
As supervisor, Dr. Nancy Mayo oversaw all aspects of the PhD project throughout for design, analyses and writing of the manuscripts. She also provided expertise regarding advanced statistical techniques such as Rasch measurement theory and group based trajectory modeling.

Dr. Susan Bartlett (co-supervisor) provided expertise about concept development, qualitative analysis of secondary data, and about how to use clinical experience to help translate ideas and results into clinically meaningful information for rehabilitation and medical professionals.

Dr. Carol White collected the original data used in Manuscript 2 and oversaw the methods used in this project and provided considerable input into the methodological content and results. Dr. Ana Maria Rodriguez provided input into the analysis for Manuscript 5 and provided substantive editorial feedback.

To summarize, all manuscripts are co-authored by the candidate’s supervisors, in addition to an expert for Manuscript 2 and Manuscript 5. The candidate, however, is responsible for the originality of the ideas, the scientific quality of the research, and for the quality of the reporting.

Statement of Originality

My graduate level training started at Queen’s University while working full time at Providence Continuing Care Mental Health Services in Kingston, Ontario as an Occupational Therapist. As a clinician, I treated individuals with serious mental illness and grew frustrated by the lack of evidence available for the interventions we were providing as a multi-disciplinary team. As a result, I
pursued my Master’s and completed a small pilot randomized controlled trial of the effectiveness of a community based self-management program for people with serious mental illness. The experience fueled my passion to continue on in research, but also made me realize that in order to be an independent researcher in the field; I needed to develop a stronger methodological and statistical skill set for designing studies and analyzing complex longitudinal mental health data. This insight led me to continue on in my learning journey and pursue a PhD at McGill University under the supervision of Dr. Nancy Mayo and Dr. Susan Bartlett.

Working with both supervisors was a special opportunity for me to apply my mental health knowledge in a new context: stroke rehabilitation. While this work could not be completed with the input and innovation of both supervisors, the studies presented in this thesis are my own original work.

This research focuses on the emotional impact of rehabilitating from, or caring for a person with a chronic illness or disability. It has been suggested that aging with, or without a disability or chronic illness, should no longer be defined solely as a freedom from physical or cognitive decline, but rather a level of satisfactory psychological functioning that optimizes function and quality of life. Thus, this research conceptualizes the emotional vitality as a construct of importance for rehabilitation specialists who work with individuals with chronic health conditions and their caregivers.

To my knowledge, there are no published reports on the sequential steps of understanding and measuring emotional vitality of caregivers. Nor have studies
investigated changes in the emotional vitality of family caregivers of stroke survivors in the first year of caregiving.

Therefore, this thesis makes an original contribution to the domain of family caregiving, specifically in the area of stroke. It also makes a contribution to the field of measurement, outlining the role of modern psychometrics to support the development of a measure.
Acknowledgements

I would like to acknowledge the financial support that I received during my PhD program from the Heart and Stroke Foundation of Canada, the Research Institute at the McGill Health Center, the McGill Faculty of Medicine, McGill School of Physical and Occupational Therapy, and the Canadian Association of Occupational Therapy.

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INTRODUCTION

It is estimated that over 650 million people worldwide live with a chronic illness or disability.\(^1,2\) The consequences of chronic health conditions have far reaching implications for individuals, families, and society. Individuals usually view the onset of a chronic illness or disability as a negative life event that can be described by some as a “psychological darkness”.\(^3\) Individuals may experience loss of valued roles, poor self-esteem, and a diminished sense of self-efficacy.\(^4\) In order to maintain quality of life and buffer the impact of stressors associated with the new health state, the development and use of adaptive psychological coping strategies are needed.\(^7,8\)

This is especially true for individuals who experience a stroke and their caregivers. Stroke is one of the leading causes of disability affecting up to 50,000 Canadians each year.\(^9\) Due to the complex nature of stroke, and the potential for unending disability, many aspects of a person’s life are affected after such a medical event. As a result of policy and a societal shift from institutional care, up to 80% of individuals with stroke return home, often placing a new unexpected caregiver role on family members.\(^9\) In addition to a sudden change in lifestyle and role loss, caregivers of stroke survivors are often faced with a multitude of new problems such as learning quickly how to manage their loved one’s demand for physical care, high risk of dementia after stroke onset, and a number of cognitive impairments.\(^10\) Caregivers are often aging spouses who are expected to master new skills quickly, all while attempting to balance caregiving with their other activities, such as work, family, and leisure. It is no wonder that the sudden onset of the caregiving responsibility has been associated with subsequent
psychological consequences, such as impairment in quality of life, more stress, anxiety, depression, and fewer social contacts than non-caregivers. Caregivers are also at greater risk for physical health problems and premature mortality compared to non-caregivers. Despite the well recognized potential hazards of family caregiving in the last two decades, only recently has there been an urgent call for health care professionals to also address the needs of caregivers and recognize them as “hidden patients” who are at high risk of suffering serious adverse physical and mental health events as the result of the demanding work and reduced attention to their own well-being and health.

Emotional vitality is an emerging concept that describes an individual’s overall sense of energy, positive well-being, personal mastery, and emotional regulation within the broader context of emotional function. Emotional vitality may serve as a critical buffer against the strain of caregiving. However, little is known about what enables some caregivers to thrive and be emotionally vital in the caregiving role, while others may fall into a negative spiral of depression, anger and despair.

One of the limitations in understanding emotional vitality in caregivers of stroke survivors has been the lack of a definition and measurement strategy to capture this elusive construct. Such a strategy would allow for a subsequent understanding of the time course of how emotional vitality changes, and its relationship to the recovery of function of the stroke survivor, will allow for the development of caregiver specific interventions to enhance emotional vitality. The enhancement of emotional vitality, identification of those at risk for inability to cope, and development of targeted interventions will facilitate the recovery of care
recipients and the retention of family members in the caregiving role.

Furthermore, it has potential to enhance post-stroke management in Canada.

**Research Purpose and Objectives**

The overall aim of this research was to contribute to the understanding of the caregiving experience. This work has three distinct components: (i) construct investigation; (ii) construct measurement; and (iii) construct impact and determinants.

The specific objectives of this work were:

i) To describe the scope and breadth of knowledge currently available regarding the definition and measurement of emotional vitality in persons with chronic health conditions;

ii) To measure the extent to which emotional vitality changes in the first caregiving year;

iii) To measure the extent to which the functional and recovery profile of stroke survivors impacts a caregiver’s emotional vitality during this period.
CHAPTER 1

Stroke is one of the leading causes of disability affecting up to 50,000 Canadians each year. The public impact of stroke extends far beyond the recipient of care to include the family caregiver. As a result of policy and a societal shift from institutional care, up to 80% of individuals with stroke return home, often placing a new unexpected caregiver role on family members. Caregivers of stroke survivors provide unpaid assistance to their loved ones to live safely and comfortably at home. The work requires a significant investment of physical and emotional resources to reorganize family roles and priorities, acquire new skills to cope with complex medical needs and healthcare systems, and create new sources of support. Although returning home is highly desirable for most, supporting family members can become overwhelmed rapidly by responsibilities. Therefore, it is not surprising that caregiving is associated with adverse health and personal outcomes such as increased fatigue, mood disorders, social isolation, functional decline and mortality. In addition, caregiver burden is associated with similar poor health outcomes for the care recipient, sometimes leading to re-admission to hospital or nursing home placement.

1.1 Defining the family caregiver

Family caregivers, often referred to as informal caregivers, constitute the largest group of care providers in North America, providing the majority of long-term care services to individuals with chronic health conditions. Throughout the thesis, the term ‘informal caregiver’ is used interchangeably with family
caregiver or caregiver. This differentiates the term from *formal caregivers* who provide health and community-support services (i.e., health professional, care coordinator, homecare assistant) and are typically compensated financially for their time.

1.2 The cost of caregiving

An estimated 4-5 million Canadians provide care for a family member with a long-term health problem,\(^9\) collectively spending more than 15.6 million hours per week at their caregiving work.\(^{33}\) In Canada, family caregivers have been described as the “invisible backbone” of the health and long term care system, providing approximately 80-90% of care needed by individuals with long-term health conditions, and contributing more than $26 billion dollars of unpaid work annually to the health care system.\(^{17,34,35}\) This can be compared to estimated costs in the United States, United Kingdom, and Australia where the annual economic value of unpaid care is estimated to be $257, $160, and $31 billion dollars respectively.\(^{36,37}\) The estimated market value of caregiver activity for persons who have experienced a stroke exceeds that spent on formal health and nursing home care.\(^{17,26,34}\) Without family caregiver assistance, care costs would increase dramatically, as many stroke survivors would require nursing home care to meet their basic needs.\(^{17,26,38}\)

1.3 How are Canadian caregivers supported?

Recognition of the invaluable contribution of informal caregivers to the health care system has resulted in repeated calls for increased levels of support for this group. In 2001, in a Speech from the Throne, the Government of Canada announced its intention to improve the support available for caregivers of
individuals with health conditions and disabilities. However, a recent report indicated that only 11% of Canada’s caregivers feel they receive any form of formal support or resources to complete caregiving duties. In November 2012, an editorial published in the Canadian Medical Association Journal suggested three measures of support be implemented immediately to support Canadian caregivers including: (1) direct financial support so that caregivers have some income security; (2) increase services such as education, respite, and training for both caregivers and those being cared for; and (3) the establishment of support and resource groups for caregivers in all provinces and territories.

On January 1st, 2012, the ‘Family Caregiver Tax Credit’ was initiated by the Government of Canada to provide tax support for caregivers of dependent family members. Regarding the second and third recommendations, education-based programs currently exist nationwide to help caregivers of stroke survivors. However, studies reporting on the effectiveness of these programs and social services show little impact on patients and only modest improvements in psychological and social outcomes in caregivers. Currently, most studies focus on the physical aspects of functioning in caregivers, and ignore the more complex components of the caregiver’s health such as emotional well-being and quality of life. In many of these programs, the caregiver simply received information about the health condition, with little attention to the range of needs associated with caregiving including coping strategies, problem-solving, stress management and self-care strategies.
1.4 Emotional Vitality

This thesis is about the emotional vitality of family caregivers of persons who experienced a stroke. Emotional vitality is an emerging concept of psychological factors that are characterized by a sense of positive energy and effective emotional regulation in order to be interested, engaged and productive in life. One of the limitations in understanding emotional vitality has been the lack of consensus on a definition or identification of relevant domains within this construct. For example, it has been described as encompassing a sense of personal mastery and happiness, while having few symptoms of depression and anxiety. It has also been represented more broadly as the capacity to adapt positively to changing roles and responsibilities and maintain emotional well-being in the face of catalytic events such as illness or disability. The term emotional vitality has also been used interchangeably with other terms such as emotional reserve, motivational reserve, and emotional resiliency, particularly when describing the ability to adapt and cope with change and remain engaged and interested in life activities. Others have made specific reference to personal resources such as happiness, motivation, confidence, and the ability to reframe and reinterpret stressful situations. Taken together, these descriptors suggest that emotional vitality embodies core values related to an inner resource that individuals can draw upon to combat arising sudden stressors such as health events, physical decline, or life changing experiences. Recognition and nurturing of this resource by healthcare professionals may help promote emotional and physical health and quality of life for both caregivers and care recipients.
1.5 Quantifying Emotional Vitality in Caregivers

With a construct as complex as emotional vitality, its measurement becomes pivotal to further advancement.

An important limitation to enhancing emotional vitality in caregivers has been the paucity of validated measures available to reliably quantify this construct. While emotional vitality encompasses the spectrum of human emotions ranging from depression and despair, to happiness and elation, most studies only use a single index such as The General Well-Being Schedule (GWBS) thus capturing only selected elements of the construct. In a landmark study of 6,025 people followed for an average of 15 years in the National Health and Nutrition Examination Survey, higher “emotional vitality” was associated with a lower risk of coronary heart disease. Yet, emotional vitality was estimated by combining some of the items from three subscales (vitality, sense of positive well-being, and emotional self-control). Other studies have combined items from different sources such as the Center for Epidemiological Studies-Depression Scale and the Geriatric Depression Scale to infer levels of emotional vitality from the absence of depressive symptoms, while others have used combinations of measures such as the Personal Mastery Scale and the Self-Esteem Scale to capture the construct.

Measurement is a science which involves description and quantification. Historically, assessment tools were developed to measure physical qualities such as weight, height, distance, and temperature. Measuring physical characteristics in rehabilitation is based on rigorous principles of quantity, number, and exactitude.
to meet the criteria of objective measurement.\textsuperscript{65} For example, measurement of range of motion, strength, gait speed, and distance can all be compared against a standard unit to establish quantitative differences that represent numerical magnitudes on an equal interval scale.\textsuperscript{65} Measuring psychological attributes and personal characteristics such as emotions, attitudes and perceptions is more challenging as these latent traits cannot be observed directly and can only be inferred by querying attitudes, thoughts and behaviors thought to reflect the underlying construct.\textsuperscript{66}

Hence, emotional vitality traditionally has been inferred by analyzing responses thought to reflect key domains of an underlying personality trait.\textsuperscript{19-23,51} Latent constructs are often captured by summing the responses from patient-reported outcomes (PROs). PROs collect meaningful information about the perceptions an individual may have about the impact of disease and treatment on health and functioning. As Turk and colleagues\textsuperscript{67} note, this may include an evaluation of an individual’s “health status, symptoms, adherence to treatment, satisfaction, and the impact of disease on functioning and well-being” (p.208). Responses are often collected directly from the individual receiving care, although sometimes the information is obtained from a caregiver or family member. One of the most common types of PROs measures commonly used to assess outcomes is health-related quality of life (i.e. SF-36),\textsuperscript{68-70} and many are designed and validated in health conditions such as stroke,\textsuperscript{71} arthritis,\textsuperscript{72-75} cancer,\textsuperscript{76-78} and depression.\textsuperscript{79,80}
1.6 Statistical Challenges associated with Patient Reported Outcomes

Measurement of constructs that are not directly observable relies on inferring the latent construct from a person’s responses to a series of questions. A “total” score to represent the construct is usually made by summing the responses on a Likert Scale to the posed questions. This approach has many limitations, not the least of which is the assumption that the numerals assigned to each category are additive and each item contributes equally to the total score.\textsuperscript{81,82} The following section summarizes the statistical challenges associated with many existing PROs.

*Ordinal treated as interval.* There are four types of scales that are used to elicit information: nominal, ordinal, interval, and ratio. In rehabilitation, the majority of the PROs used are comprised of various questions with ordinal responses. An ordinal scale orders the category response options, but unlike interval scales, it does not define the magnitude of the interval between the categories.\textsuperscript{83} Ordinal scales have an obvious hierarchy to the scoring; however, the spacing between response options is not necessarily equal. Response options are often derived from commonly used rating scales such as “excellent”/ “very good”/ “good” / “fair”/ “poor”.\textsuperscript{71}

Tools used to measure physical properties (e.g., height and weight) have units that are both calibrated and understood. In contrast, latent constructs are commonly assessed using the typical Likert scoring system (i.e. 1, 2, 3, 4, 5). One cannot assume that the numerals used to represent Likert categories have equally spaced intervals.\textsuperscript{84} For example, one cannot state that being “fair” is twice as good
as being “poor.” A common error in health sciences is that ordinal indices are summarized and reported as interval-like measures. Ordinal PROs assign a numeral to a response and the construct is then quantified by summing the ordinal response of each item to create a total score. The addition of item numerical scores assumes that each numerical response option contributes equally to the total score. However, the category labels to response options of these indices may not be equally distanced and therefore should not be summarized using traditional statistics such as mean and standard deviation. Raw scores from ordinal measures provide arbitrary numerical assignments that preserve rank order, but ignore scale magnitude. Ignoring scale non-linearity leads to rank orders that are masqueraded as scale structures.

**Comparison across studies.** A second problem with PROs is that using non-linear raw scores makes comparisons across individuals and studies difficult. For example, nonlinear item difficulties can lead to measures that offer different scores for persons of equal ability. The traditional strategy to deal with this problem is to correlate raw scores or compute standardized effect sizes; however, Bezrucko argues that this sets up a common delusion among researchers that high reliability compensates for non-linearity.

**Underestimating treatment effects and distorted significance testing.** A third problem with analyzing PROs as interval-like measures, is that the use of untransformed raw scores can underestimate the treatment effect for persons in the distribution tails of a normal distribution. Analysis that uses raw scores and relies on central distributions, can result in distorted test results. This may
occur even when scores are highly reliable. For example, raw scores in a study may indicate that a particular intervention was effective, when a linear measure would have shown no difference. The optimal solution to this problem is to eliminate raw score comparisons all together and implement the use of measures that have linear units.

Grading the performance of items. With an ordinal measure, it is also assumed that different items are assigned equal value, even though their level of difficulty differs. When assessing performance of an individual, easy and difficult items are assigned the same value. The tasks that an individual is capable of are not associated with a defined level of item difficulty. A total score from ordinal indices can misinterpret a person’s true ability, and makes the interpretation of scoring between individuals even more challenging.

Conceptual homogeneity of the items. Another challenge with many existing PROs is that they often produce a single total score even though they are multi-dimensional in nature. A PRO is multi-dimensional if it assesses multiple constructs. When several constructs are being measured, an overall summary score of all items included in the measure may not be readily interpretable. Rather, for multi-dimensional constructs a multitude of indices to quantify all aspects of this construct are often needed. For example, to measure emotional vitality, it may be important to include domains that assess depressive symptoms, anxiety, positive affect, motivation, and coping.
Researcher and Patient Burden. With lengthy questionnaires requiring significant patient and interviewer time to complete, the response burden is high, especially when repeated assessments are required.\textsuperscript{88} In order to comprehensively measure an area of functioning, several different tests and indices may be needed. Generic PROs also may not be sensitive enough to capture individual differences or may query domains that are not relevant for a particular individual, a clinical setting, or researcher objective.\textsuperscript{88}

1.7 Modern Psychometrics to understand latent constructs

Modern psychometric approaches can address many of the limitations of classically developed PROs and can offer more precise, valid, and efficient tests with scores that are clinically meaningful and interpretable. These approaches are guided by two schools of thought: (1) Item Response Theory (IRT),\textsuperscript{89,90} and (2) Rasch Measurement Theory (RMT)\textsuperscript{91,92} which have gained importance in PRO assessment compared to the Classical Test Theory (CTT) where models are based on a score that sums the responses to items.\textsuperscript{93}

IRT is a statistical modeling paradigm that is used to find mathematical models that explain data.\textsuperscript{94} This approach to measurement outlines a process whereby a researcher collects data and finds a model that will fit the data. The model that accounts best for the data is the model that is chosen.\textsuperscript{87} In comparison, RMT has been described as an experimental psychometric paradigm used to examine the extent to which observed rating scale data fit the assumption of an underlying hierarchical construct.\textsuperscript{91,95} Items and people that do not fit this underlying model would then be the focus of further study to understand their
unexpected behavior. Developing measures using Rasch Measurement Theory is increasingly popular in health and rehabilitation outcomes research. Prominent advocates in the field encourage the use of Rasch Measurement Theory for the development and testing of new patient reported outcomes to increase precision, reliability and validity of measurement in rehabilitation science. As mentioned previously in the introduction, RMT will be discussed at length in Chapters 4 and 5 of this thesis.

Summary

Emotional vitality may be a resource within the grasp and control of stroke caregivers. Before it becomes a valuable target for psychosocial and rehabilitative interventions, future development of a theoretical and measurement model for emotional vitality is needed to help identify areas where interventions can be offered to support this vulnerable population. The following chapters will summarize studies used to develop a meaningful and interpretable way to understand emotional vitality as a construct of importance for the field of rehabilitation science.
CHAPTER 2: Manuscript 1. Emotional Vitality: Concept of Importance for Rehabilitation

Preface to Manuscript 1

Manuscript 1 provides the basis for the conceptualization of emotional vitality as an important concept to consider for the field of rehabilitation. It is estimated that over 650 million people worldwide live with a chronic illness or disability. The consequences of chronic health conditions have far reaching implications for individuals, families, and society. Individuals usually view the onset of a chronic illness or disability as a negative life event that can be described by some as a “psychological darkness”. Individuals may experience loss of valued roles, poor self-esteem, and a diminished sense of self-efficacy.

In order to maintain quality of life and buffer the impact of stressors associated with the new health state, the development and use of adaptive psychological coping strategies are needed.

Emotional vitality is an emerging concept of psychological factors that may facilitate recovery and enhance physical and mental health after experiencing a stressful event. It goes beyond the concept of coping and is characterized by an overall sense of energy, positive well-being, and the ability to regulate emotions effectively. Relatively little is known about what enables some individuals to thrive and be emotionally vital after a stressful event, while others fall into a negative spiral of depression and despair. Emotional vitality may be an important psychological resource that serves as a critical buffer against the strain of living with a chronic illness or disability. If emotional vitality is indeed associated with
or predictive of positive health outcomes, it would serve as a valuable and modifiable new target for intervention.

To date, no definition or measure of emotional vitality has been agreed upon. For example, emotional vitality is defined by Kubzansky as a person’s sense of energy and positive well-being, and ability to regulate emotions effectively. It is also described as a combination of a person’s sense of personal mastery, state of happiness, and level of depression and anxiety. Other terms that have synonymously been used to describe the construct are: emotional resilience, emotional reserve, and human flourishing. In positive psychology literature, the term resilience is often used to refer to a person’s ability to bounce back from adversity. In some studies, the focus is on the more stable personality traits such as usual ability to adapt to change, cope, have humour, and re-interpret stressful situations more positively. Among other researchers, emotional resiliency encompasses these stable traits and the potentially modifiable states that our group hypothesized to include energy, happiness, motivation, confidence, and calmness.

In addition, the measurement of emotional vitality in many studies has been poor, with both theoretical and measurement flaws. It is understood that emotional vitality encompasses the spectrum of human emotions ranging from depression and despair, to happiness and elation. Yet, most studies measuring emotional vitality only use a single index such as The General Well-Being Schedule (GWBS) to capture one part of the construct. In a landmark study of 6,025 people followed for an average of 15 years in the National Health and Nutrition Examination Survey, higher “emotional vitality” was associated with a
lower risk of coronary heart disease. Yet only the GWBS was used as an index of emotional vitality by combining some of the items of three of the subscales (vitality, sense of positive well-being, and emotional self-control). Other studies\textsuperscript{21,62} combined many items from different sources such as the Center for Epidemiological Studies-Depression Scale\textsuperscript{80} and the Geriatric Depression Scale\textsuperscript{61} to infer levels of emotional vitality.\textsuperscript{21,62} Some studies\textsuperscript{13} have used a composite of validated and widely used measures such as the Personal Mastery Scale\textsuperscript{63}, the Self-Esteem Scale, and the NEO-PI (neuroticism, openness, and extraversion scale) to capture the construct. Heterogeneity of measurement approaches makes the interpretation of the results very difficult to generalize and compare across studies.

While emotional vitality may serve as a critical buffer against the strain of living with a chronic illness or disability, yet very little is known about what enables some individuals to thrive and be emotionally vital in the process of recovery and adaptation. If emotional vitality is indeed associated with or predictive of positive health outcomes, it would serve as a valuable and modifiable new target for rehabilitation intervention in order to optimize health outcomes for people with chronic health conditions.\textsuperscript{111-115} However, in order to support and enhance emotional vitality in individuals with chronic health conditions, a definition and measurement strategy are first needed. A comprehensive understanding of patient and provider-valued components of emotional vitality will lead to a measurement approach and the potential emergence of a focused rehabilitation research agenda.
The overarching aim of the following manuscript was to lay a framework for the conceptualization of emotional vitality as an important construct for people with chronic health conditions or disabilities. The specific objectives were to outline the existing scope and breadth of knowledge currently available regarding the definition and measurement of emotional vitality in persons with chronic health conditions, and identify the extent to which the components can be mapped to the International Classification of Functioning, Disability, and Health (ICF).

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Emotional Vitality: Concept of Importance for Rehabilitation

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Running Head: Emotional Vitality
ABSTRACT

Objective: To provide a framework for the conceptualization of emotional vitality as an important construct for rehabilitation professionals. The specific objectives are to outline the existing scope and breadth of knowledge currently available regarding the definition and measurement of emotional vitality in persons with chronic health conditions, and identify the extent to which the components can be mapped to the International Classification of Functioning, Disability, and Health (ICF).

Design: Activities included a scoping review of the literature, and a Delphi mapping exercise using the ICF.

Setting: not applicable.

Participants: not applicable.

Intervention: not applicable.

Main Outcome Measure: not applicable.

Results: The results of this study suggest that emotional vitality is a complex latent construct that includes: (1) physical energy and well-being, (2) regulation of mood, (3) mastery, and (4) engagement and interest in life. Existing literature supported the presence of all four components of the construct. The mapping exercise showed that three of these components could be readily mapped to the Body Function chapter of the ICF (energy, mood, and mastery).
**Conclusion**: Emotional vitality may influence both the physical and emotional adaptation to living with a chronic illness or disability and should be included in both assessment and treatment planning to optimize rehabilitation outcomes. Future research is needed to refine the definition and identify optimal methods of measuring this construct.

**Keywords**: positive emotion; vitality; rehabilitation

**Abbreviations**: ICF (International Classification of Functioning, Disability, and Health)
Introduction

Rehabilitation specialists work with individuals whose function has been altered by disease, injury or natural processes such as aging. While the physical aspects of function have been well defined and measured, facilitating the development of clinically effective interventions, and understanding and addressing the emotional response to functional loss has not been systematically addressed. Increasingly referred to as “hidden disabilities”, the emotional aspects are often described using heterogeneous terms such as energy, personal mastery, regulation of mood, motivation, and resilience. While many of these domains fall within the scope of the disability literature and practice, in physical rehabilitation they are often considered challenging to address. Viewing physical and emotional adjustment to chronic illness and injury as separate processes may result in overlooking the reciprocal nature that each has on the other and increases the likelihood that emotional well-being may not be adequately addressed.

Emotional vitality is a term that has been used to characterize an individual’s emotional response to adjusting to life with a chronic illness or injury. While emotional vitality may serve as a critical buffer against the strain of living with a chronic illness or disability, very little is known about what enables some individuals to thrive and be emotionally vital in the process of recovery and adaptation. If emotional vitality is indeed associated with or predictive of positive health outcomes, it may serve as a valuable and modifiable new target for intervention. Emotional vitality may be a construct within an individual’s
control and there is much to learn about how an individual’s emotional resources may optimize health and rehabilitation outcomes.

However, in order to support and enhance emotional vitality in individuals with chronic health conditions, a definition and measurement strategy are needed. A comprehensive understanding of patient and provider-valued components of emotional vitality is essential to developing the appropriate measurement approach and the potential emergence of a focused rehabilitation research agenda informing practice.

The premise is that emotional vitality is an important construct in rehabilitation. If it is within the purview of rehabilitation, components of the construct should be represented in the nomenclature already defined for the field. The World Health Organization’s International Classification of Functioning Disability and Health (ICF), provides a universal language and conceptual framework for describing health and disability. The ICF has been used as a basis for establishing content validity for minimum data sets and measures in a variety of health conditions. Our hypothesis is that if the ICF contains domains describing components of emotional vitality, then emotional vitality lies within the scope of measurement and practice of rehabilitation professionals.

The goal of this paper is to lay a framework for the conceptualization of emotional vitality as an essential construct to address in both the assessment and treatment of people experiencing functional consequences of a health event. In this paper, the scope and breadth of knowledge currently available regarding the definition and measurement of emotional vitality in persons with chronic health
conditions are outlined and the extent to which components of emotional vitality can be mapped to the ICF classification system is identified.¹

Methods

The objectives were addressed using two different methodologies: 1) a scoping review of the literature, and 2) Delphi mapping exercise among rehabilitation health professionals using the ICF.

Study #1: Scoping Review

The aim of the scoping review was to broadly map the key domains underpinning the construct of emotional vitality and identify empirical evidence currently available to measure emotional vitality in individuals with chronic health conditions. Scoping reviews can be used to explore specific questions in the existent literature.¹¹⁸ As compared to systematic reviews, scoping reviews provide an overview of current knowledge and practices, but do not evaluate the methodology or quality of studies currently available.¹¹⁸,¹¹⁹ The five stage methodological framework¹¹⁸ to conduct this type of review was followed including: identification of the research question; (ii) identification of all pertinent studies; (iii) selection of the studies for detailed analysis; (iv) charting of the data according to key concepts; and (v) collation and summarization of the findings from selected studies.

i) Identification of the Research Question

Three questions were used to guide the review: (1) “How is emotional vitality defined in the literature?; (2) How is emotional vitality measured?; and (3) What
is known from the existing literature about the effectiveness of behavioural interventions that target components of emotional vitality in individuals with chronic health conditions?

ii) Identification of Pertinent Studies

All relevant studies were identified regardless of publication status (published, unpublished, in press, and in progress). Four electronic databases were searched including [PSYCInfo (1967 to June 2012), MEDLINE (1966 to June 2012), EMBASE (1980 to June 2012), and Cumulative Index to nursing and Allied Health Literature (1960 to June 2012)] using the terms “emotion*” AND “vitality” as key words. The search was also conducted in the Trials Register of the Cochrane Depression, Anxiety, and Neurosis Group, and the Cochrane Central Register of Controlled Trials (CENTRAL). The grey literature was also searched in: Conference papers Index, Dissertation abstracts, and the Dissertations and Theses database (USA, Canada, Scandinavia, and the United Kingdom) from 1980 to June 2012. The reference lists of all of the relevant articles were screened. Several colleagues in the field were also contacted and asked to identify any relevant published or unpublished papers on the topic that may have not been found in the initial search.

iii) Selection of the Studies for Detailed Analysis

Initially, the titles and abstracts of all studies identified by electronic searchers were independently screened by two authors to shortlist studies for this review. We included all available articles published in English or French that described or measured emotional vitality in adults. Seven articles were excluded (5 were
published in Chinese, one in Estonian, and another in German) due to the cost of translation. No methodological limitations were applied to screen for levels of evidence.

iv) Charting of the data according to key concepts and measurement strategies

Studies were synthesized and sorted according to key issues and themes. Studies were synthesized and sorted according to key issues and themes. Author, year of publication, intervention (type, comparator, and duration of intervention), study population, aims of the study, type of methodology, and outcome measures that were recorded. Articles were then reviewed, sorted and categorized in three ways: (a) definitions, (b) measurement strategy, and (c) study design.

v) Collation and Summarization of the Findings of Selected Studies:

Next, we created a summary of each study without regard to assessment of study quality or the “weight” of evidence in relation to particular interventions.

Study #2 ICF Mapping Exercise:

The specific objective of this study was to estimate the extent to which categories in the Body Function chapter of the ICF were identified as representing emotional vitality. This chapter was chosen for content purposes because we wanted to capture the physiological processes contributing to emotional vitality rather than the consequences of impaired emotional vitality which would be represented in other chapters (Activity and Participation), recognizing that the
domains in the other chapters would not uniquely be impacted by emotional vitality.

Participants

Twenty-five health professionals and graduate students were recruited from an academic health university setting. Professionals came from a number of different backgrounds including medicine (n=2), psychology (n=4), occupational therapy (n=3), physiotherapy (n=8), epidemiology (n=4), and exercise physiology (n=4). The participants had an average of 10.2 years (range 0-38 years) in clinical experience, 2.9 years of research experience with the ICF in research (range 0.5-10 years), and 1.3 years (range 0-10 years) of clinical experience with the ICF.

Procedures

Participants were asked to identify ICF Body Function categories that fit within their conceptualization of emotional vitality. In the ICF classification, each category is given an alphanumeric code with the number of digits reflecting the granularity of the category. A Delphi technique using a threshold of 70% was used to gain consensus on the ICF categories related to emotional vitality. The Delphi technique was chosen as it ensures the contribution of each participant is equally recognized, regardless of discipline or years of experience.

In the first round, a spreadsheet with all ICF codes from the first chapter of the ICF, along with a link to definitions on the electronic version of the ICF was provided, along with a copy of the ICF book if desired. The participants were
asked to indicate all codes that they felt captured the construct of emotional vitality.

In round two, a second spreadsheet containing frequency of responses for each category from round 1 was emailed to participants one month later. Participants were asked to review the responses provided by other participants and consider if they wished to choose the same or a different category from the ones initially selected in round one, or alternatively remove a category.

**Data Analysis**

All 25 spreadsheets were returned in both rounds. Each spreadsheet was assigned a code and entered and the data were entered into a separate spreadsheet for analysis. Percent agreement was calculated for each category as the number of people who identified that category as a component of emotional vitality.

**Results**

*Study#1: Scoping review.*

From the initial 3109 citations, 87 were subjected to full text review and 11 were ultimately included in the scoping review (see Figure 2.1). Table 2.1 provides a summary of health conditions, samples sizes, definitions, and measurements strategies used by these 11 studies. All studies provided a definition and/or conceptual framework for emotional vitality and seven studies specified a measurement strategy. No behavioural intervention studies were found that specifically targeted emotional vitality.

**INSERT TABLE 2.1 HERE**\(^{19-22,51-53,60,61,63,80,125-127}\)
Trends in reviewed studies:

Our scoping review identified several themes. First, although the definition of emotional vitality was not consistent across studies; key components such as regulation of mood were commonly included in most definitions. Other common domains included energy and well-being (n=5), \(^{20,51-53,128}\) engagement and interest in life (n=5), \(^{20,51,52,128}\) and mastery (n=4). \(^{21,22,125,127}\) To measure emotional vitality, six studies used items from validated scales to infer emotional vitality.\(^{19,21,22,51}\) (see Figure 2.2).

Study #2: Mapping Results:

Eighteen domains were mapped to the ICF, reflecting 13% of the possible codes available in the Body Structure/function chapter. Almost all (17) were mapped at the 4 digit level, with one domain at the 3 digit level (see Table 2.2). Common categories were identified including: 1) energy, 2) mood, and 3) control of thought/mastery.

Discussion

Taken together, the scoping review and ICF mapping Delphi exercise, support the existence of emotional vitality as an important component of rehabilitation. The scoping review identified four domains including: (1) physical health, (2) regulation of mood, (3) mastery, and (4) engagement in other roles and activities. The Delphi mapping exercise showed that three of these components could be mapped using the Body Function chapter of the ICF (energy, mood, and mastery).
Emotional vitality is highly relevant to rehabilitation activities and warrants attention from our field. It has been suggested that aging with, or without a disability or chronic illness, should no longer be defined solely as a freedom from physical or cognitive decline, but rather a level of satisfactory psychological functioning that optimizes function and quality of life. This includes freedom from depression, moderate levels of physical activity, and self-perceived wellness. Thus, attending to the emotional vitality of individuals with chronic health conditions is essential to ensuring the spectrum of rehabilitation care is comprehensive and effective.

One of the limitations in routinely addressing emotional vitality in individuals with chronic illnesses or disabilities has been the lack of a consistent definition and measurement strategy to capture this construct. Our results show that at least four components potentially make up the construct. However, further consensus and inclusion of patient perspective are needed to develop an agreed upon definition. Focus groups with individuals with chronic health conditions and disabilities are needed to further ensure the patient perspective is included when defining this construct.

If indeed emotional vitality is modifiable and can contribute to achieving positive health outcomes, reliable and valid measurement is essential to further advancement. To date, measurement approaches have varied widely, hampering efforts to compare results across studies. For example, some assess emotional vitality with a single index such as the General Well-Being Schedule (GWBS) or by combining items from several subscales such as the Center for Epidemiological Studies-Depression Scale (CES-D) and the Geriatric
Depression Scale (GDS),\textsuperscript{61} inferring that emotional vitality is the inverse of depressive symptoms. Indeed the term vitality is pervasive in the literature, perhaps reflective of two commonly used measures, the SF-36\textsuperscript{68} and the Profile of Mood States (POMS),\textsuperscript{132} which label one of their constructs as “vitality”. In both of the measures, this term is intended to reflect the continuum of energy, and fatigue is conceptualized as representing low levels of energy.\textsuperscript{133} However, our results suggest that emotional vitality reflects more than simply energy/fatigue and should be assessed with items that capture all relevant domains.

Commonly, health has been viewed as the absence of illness only, and research has been based on the untested assumption that health and illness form a dichotomous dimension.\textsuperscript{134} As early as 1948, health was defined by the World Health Organization\textsuperscript{135} as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. A mere half century later, there is now a shift in thinking towards the understanding the complexity of health and the reciprocal influences of psychological health on illness and disability.

Traditionally, emotional health has been conceptualized as the relative freedom from depression and anxiety. However, increasingly mental health is viewed as more than just the absence of symptoms, but the presence of positive affect as well.\textsuperscript{136} There is evidence that it is possible to be diagnosed with a mental illness and yet still experience relatively good mental health. Conversely, it is also possible to be free of a diagnosis, but be languishing emotionally and have poor mental health.\textsuperscript{134,136} This idea is very important when capturing the construct of
emotional vitality. Emotional vitality likely involves the regulation of both negative and positive mood, maintenance of energy and physical well-being, a strong sense of mastery, and engagement in meaningful activity. Each domain has the potential to be assessed and addressed by rehabilitation professionals. Consideration of a person’s emotional vitality when assessing and treating health may help optimize how rehabilitation services are delivered to individuals and improve health outcomes.

The scoping review also revealed substantial conceptual and empirical overlap between emotional vitality and other indicators of psychological well-being. For example, terms such as emotional function, emotional vigour and emotional well-being have also been used interchangeably to describe positive emotion and energy. As well, emotional resilience, emotional reserve, and human flourishing have also been used synonymously to describe an overall sense of emotional well-being which can improve health outcomes and health related quality of life. However, our results suggest that emotional vitality reflects a broader, multi-dimensional construct that goes beyond the presence/absence of emotional distress.

**Conclusion**

For centuries, there has been acknowledgement that the way people feel in their minds could influence the way they respond in their body. However, only recently has attention turned toward understanding how emotional well-being influences recovery, adaptation, and health outcomes. Rehabilitation professionals
recognize the complexity of treating individuals with chronic health conditions and disabilities. The extent to which emotional vitality can be defined, measured, and modified may lead to the development of new interventions for individuals who experience chronic illness or disability. The enhancement of patient emotional vitality, identification of those at greatest risk for inability to cope, and the development of targeted interventions for emotional vitality may optimize the rehabilitation process for many. As the number of individuals with disabilities and chronic illnesses increases dramatically with the aging population, further understanding of the impact of emotional vitality on the rehabilitation process may provide important evidence-based information to clinicians and researchers to enhance the overall experience of this vulnerable population.

Study Limitations:

While this approach to offering proof of concept has several strengths, there are also limitations. Although 11 studies were identified, it is possible that some were omitted by the search strategy. By searching the key terms of “emotion” and “vitality”, those studies that examined the construct using different terms such as mastery, mood, or energy may have been missed. In addition, in scoping reviews, the quality of each study is not formally evaluated. Another limitation was the variable level clinical experience and experience in using the ICF during the Delphi procedure. Future studies should conduct qualitative work (e.g., focus groups and/or individual interviews) to provide insight into how individuals with chronic health conditions and disabilities define emotional vitality. In addition, better definitions of potentially overlapping domains such as mastery, mood and
energy are needed to help to reduce redundancy and confusion among these constructs.
Table 2.1: Included studies for the scoping review, including definition and measurement approach for capturing Emotional Vitality

<table>
<thead>
<tr>
<th>Study</th>
<th>Population</th>
<th>Definition of Emotional Vitality</th>
<th>Measurement Strategy (if applicable)</th>
</tr>
</thead>
</table>
| Boehm                | Coronary heart disease      | Active engagement with the world, effective emotional regulation, and an overall sense of well-being.                                                                                                                                 | Total score on five items:  
  (1) I have a sense of direction and purpose in my life.  
  (2) How often do you feel emotionally or mentally exhausted at the end of the day?  
  (3) How much of the time during the past 4 weeks did you feel full of life?  
  (4) How much of the time during the past 4 weeks did you have a lot of energy?  
  (5) How much of the time during the past 4 weeks have you been a happy person? |
| Deshpande            | Elderly women               | Inferred by regulation of mood and being in control of one’s life circumstances (mastery)                                                                                                                                          | Combination of the total score of the Center for Epidemiological Studies Depression scale and Pearlin and Schooler Personal Mastery Scale |
| Richman              | Coronary heart disease      | A composite of positive emotions that provides energy for managing negative emotions and solving problems effectively.                                                                                                               | None                                                                                                                    |
| Kubzansky and Thurston | Coronary heart disease     | A sense of positive energy, and the ability to effectively regulate emotion and behavior, and positive well-being, which includes feeling engaged and interested in life.                                                       | Selected questions from the General Well-being Schedule  
  (1) How much energy, pep, vitality have you felt?  
  (2) How happy, satisfied, or pleased have you been with your personal life?  
  (3) Has your daily life been full of things that were interesting to you?  
  (4) Have you been in firm control of your behavior, thoughts, emotions or feelings?  
  (5) Have you been feeling emotionally stable and sure of yourself? |
| Fredman              | Hip fracture                | A psychological characteristic defined by a sense of emotional well-being, self-confidence, and optimism most of the time. Authors use the term “positive affect”                                                                 | Depression measured using  
  (1) Total score from the CES-D  
  (2) Positive affect inferred from total score of 4 positively worded items in the CES-D. |
<table>
<thead>
<tr>
<th>Study</th>
<th>Population Description</th>
<th>Positive and Restorative State</th>
<th>Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rozansky and Kubzansky</td>
<td>n/a</td>
<td>A positive and restorative state that is associated with enthusiasm and energy. It is further described as a composite of positive emotions, including a sense of joy and a sense of interest.</td>
<td></td>
</tr>
<tr>
<td>Pitkala</td>
<td>Elderly (n=102)</td>
<td>High sense of emotional mastery, being happy, and not being depressed or anxious.</td>
<td></td>
</tr>
<tr>
<td>Ble</td>
<td>Inpatients of internal medicine unit (n=65)</td>
<td>An overall high level of emotional functioning</td>
<td></td>
</tr>
<tr>
<td>Penninx</td>
<td>Community dwelling disabled women (n=1002, age ≥ 65)</td>
<td>High level of emotional mastery, being happy, and having low depressive and anxiety symptomology.</td>
<td></td>
</tr>
</tbody>
</table>

To be categorized as emotionally vital, participants had to fulfill all of the following criteria:

1. Have a high score (7/10) on the happiness scale,
2. Agree or strongly agree with “I can do just about anything I really set my mind to,” and disagree or strongly disagree with “I often feel helpless in dealing with the problems of life,”;
3. Not more than 1 out of 4 of a subset of anxiety symptoms on the Hopkins Symptom Checklist;
4. Low score (6/15) on the Geriatric Depression Scale.

Penninx

To be categorized as emotionally vital, participants had to fulfill all of the following criteria:

1. Have a high sense of personal mastery by disagreeing with the item “I often feel helpless in dealing with the problems in life” and agree with “I can do just about anything I set my mind to”;
2. Report a high level of happiness by scoring ≥ 8 on the happiness scale (ranging from 0 (extremely unhappy) to 10 (extremely happy));
3. Have low depressive symptomology (score <10 on the 30 item Geriatric Depression Scale);
4. Not more than 1 out of 4 of a subset of anxiety symptoms on the Hopkins Symptom Checklist.

Penninx

Same as Penninx

---

i. I felt that I was just as good as other people
ii. I felt hopeful about the future
iii. I was happy
iv. I enjoyed life
<table>
<thead>
<tr>
<th>Study</th>
<th>Population</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schwartzberg¹²</td>
<td>Dwelling disabled women (n=1002, age ≥ 65)</td>
<td>Happy, and having low depressive and anxiety symptomology.</td>
</tr>
<tr>
<td></td>
<td>Men with HIV (n=7)</td>
<td>Unhindered by undo depression or anxiety, maintenance of satisfying work and/or interpersonal relationships, active attendance to physical health, and ability to prescribe meaning to life in the chronic health condition.</td>
</tr>
<tr>
<td>Component</td>
<td>Round 2 Agreement (%)</td>
<td>% change of participant agreement</td>
</tr>
<tr>
<td>----------------------------------</td>
<td>-----------------------</td>
<td>-----------------------------------</td>
</tr>
<tr>
<td><strong>Energy</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Energy and drive functions (B130)</td>
<td>92</td>
<td>4</td>
</tr>
<tr>
<td>Energy level (B1300)</td>
<td>100</td>
<td>4</td>
</tr>
<tr>
<td>Motivation (B1301)</td>
<td>96</td>
<td>4</td>
</tr>
<tr>
<td><strong>Mood</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agreeableness (B1261)</td>
<td>76</td>
<td>0</td>
</tr>
<tr>
<td>Conscientiousness (B1262)</td>
<td>80</td>
<td>4</td>
</tr>
<tr>
<td>Psychic stability (B1263)</td>
<td>84</td>
<td>0</td>
</tr>
<tr>
<td>Openness to experience (B1264)</td>
<td>84</td>
<td>0</td>
</tr>
<tr>
<td>Optimism (B1265)</td>
<td>96</td>
<td>20</td>
</tr>
<tr>
<td>Confidence (B1266)</td>
<td>92</td>
<td>0</td>
</tr>
<tr>
<td>Emotional Functions (B152)</td>
<td>100</td>
<td>0</td>
</tr>
<tr>
<td>Appropriateness of Emotion (B1520)</td>
<td>100</td>
<td>0</td>
</tr>
<tr>
<td>Regulation of Emotion (B1521)</td>
<td>100</td>
<td>0</td>
</tr>
<tr>
<td>Range of emotion (B1522)</td>
<td>100</td>
<td>0</td>
</tr>
<tr>
<td><strong>Control of Thought/Mastery</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Control of thought (B1602)</td>
<td>80</td>
<td>4</td>
</tr>
<tr>
<td>Content of thought (B1603)</td>
<td>84</td>
<td>14</td>
</tr>
<tr>
<td>Cognitive flexibility (B1643)</td>
<td>72</td>
<td>0</td>
</tr>
<tr>
<td>Insight (B1644)</td>
<td>84</td>
<td>8</td>
</tr>
<tr>
<td>Judgment (B1645)</td>
<td>76</td>
<td>0</td>
</tr>
<tr>
<td>Problem-solving (B1646)</td>
<td>92</td>
<td>16</td>
</tr>
</tbody>
</table>
Figure 2.1: Inclusion and exclusion criteria to identify selected studies
Figure 2.2: Theoretical model of emotional vitality

- Physical Well-being & Energy
- Interest/Engagement in life
- Regulation of Mood
- Mastery
Preface to Manuscript 2

Manuscript 1 provided a general framework to understand emotional vitality as a construct of importance for rehabilitation. The goal of Manuscript 2 was to extend this work by evaluating the application of this theoretical model in a sample of caregivers of stroke survivors. These caregivers experienced a catalytic event in their lives without the direct medical consequences associated with a new onset health condition, thereby making them a unique group to further understand emotional vitality. While emotional vitality may serve as a critical buffer against the strain of caregiving, little is known about what enables some informal caregivers to thrive and be emotionally vital in the role, while other descend into a spiral of inertia, despair and hopelessness. Here, identified domains associated with emotional vitality in caregivers are described and results with those first identified in Manuscript 1 are compared.

In this study, a secondary analysis was performed of interviews from an earlier study that had been conducted with caregivers of stroke survivors. This approach offered the opportunity to efficiently identify potential domains relevant to emotional vitality and explore the content validity of our working model. The goal of the original study was to develop a grounded theory of quality of life in family caregivers of stroke survivors. During the interviews, participants were asked to describe the specific impact of assuming the caregiving role on their
physical and emotional well-being, overall energy, and ability to participate in meaningful activities. Although the research interests of this project differed from the original study, the richness of the available data allowed for the pursuit of information distinct from the original work. The secondary analysis provided a starting point to understand emotional vitality from the perspective of individuals who have experienced a catalytic event in their lives that draws directly from the concept under investigation.

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Title Page

Title: Emotional Vitality: A Concept Analysis of the Caregiver Perspective

Submitted to Qualitative Health Research February 26th, 2013

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ABSTRACT

Emotional Vitality (EV) is a new term in health research. This study describes EV in the context of the caregiving experience and proposes a working model of EV for caregivers of stroke survivors. A secondary analysis of interviews with 30 community dwelling caregivers of stroke survivors was conducted. Caregivers were asked to describe changes in their health, relationships, social roles, finances, and mood after assuming the caregiving role. Transcripts were analyzed using a bottom up discourse approach that coded key words describing the impact of the caregiving experience on EV. Identified themes important to caregiver EV were: a) physical health and well-being; b) support and recognition from others; c) engagement in meaningful activity; d) mood regulation; and e) sense of control/mastery of new skills. Health professionals can play an important role in recognizing and nurturing EV in caregivers to help promote quality of life for both caregivers and their care recipients.

Key Words: Emotions; Caregivers; Concept Analysis
Introduction

Informal caregivers of persons with chronic health conditions have been described as the “invisible backbone” of the health and long term care system, providing approximately 80-90% of the daily care required by individuals with chronic illnesses or disabilities. Informal caregivers are often family friends, or neighbors who provide unpaid assistance to their loved ones to live safely and comfortably at home. Thrust into new roles and responsibilities, caregivers must invest significant amounts of physical and emotional energy to reorganize family roles and priorities and acquire new skills to cope with complex medical needs and healthcare systems. Frequently, the investment is so overwhelming and burdensome that caregiver burnout occurs. Informal caregivers are also at greater risk for the onset of new health problems and premature mortality. There is also strong evidence for significant psychological consequences such as high levels of stress, anxiety, depression, and social isolation. Currently, recommendations exist to support caregivers in learning illness-specific rehabilitation skills to enable care recipients to remain at home in the community. However, the focus of many of these programs often overlooks the caregiver’s personal needs, in particular their emotional well-being. Supporting the emotional well-being of caregivers only becomes a priority when the caregiver’s ability to retain this role is threatened.

Emotional vitality is an emerging concept of psychological factors that is characterized by a sense of positive energy and effective emotional regulation in order to be interested, engaged and productive in life. One of the
limitations in understanding emotional vitality has been the lack of consensus on a
definition or identification of relevant domains within this construct. For example, it has been described as encompassing a sense of personal mastery and happiness, while having few symptoms of depression and anxiety.\textsuperscript{21,22} It has also been represented more broadly as the capacity to adapt positively to changing roles and responsibilities and maintain emotional health in the face of catalytic events such as illness or disability.\textsuperscript{20-22,51-53} The term emotional vitality has also been used interchangeably with other terms such as \textit{emotional reserve}, \textit{motivational reserve}, and \textit{emotional resiliency}, particularly when describing an ability to bounce back after adversity, adapt to change, cope; and have humor.\textsuperscript{53-56} Others have made specific reference to personal resources such as happiness, motivation, confidence, and the ability to reframe and reinterpret stressful situations.\textsuperscript{54,57-59} Taken together, these descriptors suggest that emotional vitality embodies core values related to an inner resource that individuals can draw upon to combat arising sudden stressors such as health events, physical decline, or life changing experiences. Recognition and nurturing of this resource healthcare professionals may help promote emotional and physical health and quality of life for both caregivers and care recipients.

To define and explore emotional vitality as an important concept for health care and health outcomes the steps outlined by Morse\textsuperscript{144} were applied. In brief, through a scoping review of 11 studies and Delphi mapping exercise of 25 research and health professionals using the International Classification of Functioning, Disability, and Health,\textsuperscript{1} four key themes were identified including: (1) energy, (2)
mood, (3) mastery of new skills, and (4) engagement in meaningful activity. The goal of this paper is to extend this work by evaluating the application of our working theoretical model in a sample of caregivers of stroke survivors. These caregivers experienced a catalytic event in their lives without the direct medical consequences associated with a new onset health condition, thereby making them a unique group to further understand emotional vitality. While emotional vitality may serve as a critical buffer against the strain of caregiving, little is known about what enables some informal caregivers to thrive and be emotionally vital in the role, while other descend into a spiral of inertia, despair and hopelessness. Here, identified domains associated with emotional vitality in caregivers are described and compared with those first identified in the initial stages of the concept analysis.

Methods

A secondary analysis of interviews from an earlier study of stroke caregivers was performed. This approach offered the opportunity to efficiently identify potential domains relevant to emotional vitality and explore the content validity of the working theoretical model. The goal of the original study was to develop a grounded theory of quality of life in family caregivers of stroke survivors. During the interviews, participants were asked to describe the specific impact of assuming the caregiving role on their physical and emotional well-being, overall energy, and ability to participate in meaningful activities. The original study was approved by the Ethics Committee at McGill University and all participants provided written consent.
Description of secondary data

Participants were 30 caregivers of community dwelling stroke survivors in the Montreal area, who were mostly female (76%), with a mean age of 54 (SD=16) years, and 21 (SD=9) months of caregiving experience (SD=9). They were more likely to be spouses (63%) than adult children (30%). About one third of caregivers were employed at the time of the interview.

The semi-structured interview guide was developed during a 2-hour focus group with 6 allied health professionals (nursing, occupational therapy, physical therapy, and social work) who had cared for stroke patients and their families in a community setting. Caregivers were asked to describe changes in their health, family relationships, social roles and responsibilities, finances, and emotional well-being that had resulted from assuming the caregiving role. Interviews were conducted in caregiver’s language of choice and lasted 30 to 45 minutes; 15 were conducted in English and 15 in French. Conversations were audio-taped and transcribed for further analysis.

Analysis

Transcripts were analyzed using a bottom up discourse approach that coded key words describing the impact of the caregiving experience. Themes were identified independently by two trained independent reviewers using the framework analytic tool outlined by Ritchie &Lewis. Steps included: 1) indexing (coding/labeling) data relevant to emotional aspects of caregiving; 2) grouping similar indexes to form overarching sub-themes; and 3) entering indexed data into the framework with themes (in columns) and participants’ stories (in
rows) providing context. Identified themes were then mapped back to the preliminary domains of emotional vitality we previously identified. Themes that could not be mapped back were collected in a separate category (other) and content analysis was used to arrange the material into sub-categories and identify additional themes. In the coding process, it was recognized that the previous work completed by our group on this topic may have served as a sensitizing framework for examining the data. Therefore, one reviewer was chosen who was not familiar with the topic under study in order to minimize bias when analyzing the data.

**Results**

Data were summarized and organized as a hierarchy of indexes, as shown in Table 3.1. Five themes emerged including: a) physical health and well-being; b) support and recognition from others; c) engagement in meaningful activity; d) regulation of mood; and e) sense of control/mastery of new skills.

*Impact on Physical and Emotional Well-being*

Caregivers described experiencing high levels of fatigue as a result of providing care and assuming new roles, which in turn had a major impact on their physical and emotional well-being and function. For example participants reported:

“**I am a lot more tired…it makes me feel so stressed out**” (P3); I have lost 30 pounds (P11); “**I am tired all the time – I am burnt out... I don’t have any energy ... I can’t sleep... my sleep is broken up... it definitely has health affects...**”
my blood pressure is up, I am very stressed and I have more headaches” (P6);
“man is not easy for me – I have started to smoke again” (P3); and “I am
trapped… I feel dizzy often, have no pep or energy” (P11).

Recognition and Support for Assuming the Caregiving Role

Recognition of changing roles and receiving support from family, friends and
healthcare professionals was viewed as important for maintaining emotional
health. Participants described feeling validated when family, friends and others
recognized the impact of the stroke on the caregiver as well as the survivor. They
also spoke of how receiving tangible and emotional support from others often
enabled them to cope more effectively with the caregiving role. For example,
participants said:

“My daughter helps me – she calls every day to see how I am doing
because she knows this is very hard for me and she has us over to dinner once a
week” (P8); “I couldn’t do this without my son” (P12); and “I have some help from
friends to keep up my yard... most people don’t understand what I am going
through or how much energy it takes to look after someone who is not well” (P7);
and “he’s not my husband anymore – we don’t have a relationship – I am his
caregiver – our marriage ended with his stroke – he has his room and I have mine
– his stroke and caregiving have affected my relationship with his children – they
have alienated me” (P6); “the system could have provided more psychological and
emotional support; also a long-term follow-up of how we are doing would be
important” (P20); “we did not get as much help as we needed – I could have used
more respite, especially at the beginning, my questions were poorly addressed by the CLSC” [local community health clinic] (P29).

Engagement in Meaningful Outside Activity

Caregivers noted that they often felt constrained and at times overwhelmed by the need to take on new roles associated with caregiving, as well as the importance of being able to take breaks on occasion and engage in meaningful activity. This included volunteering, returning to work, or simply performing activities of daily living. Examples included: “it pre-occupied my whole life – I had to give up all my activities and sports so that I could be available to help her but now as she is improving, I am having a little more time for myself” (P21); “it is more difficult to go out – I feel more confined” (P14); “I cannot go out for any longer than 30 to 60 minutes – I always feel rushed when I go out – rushed to go to the hairdresser, rushed to see my doctor” (P10); “I stopped employment completely because of caring for my mother – financial repercussions – now only my husband’s pay cheque” (P1); “I felt very isolated at home” (P9); “this has taken a big toll on me – I am juggling between my job, my husband and children, my husband’s business and caring for my mother – sometimes I can’t see any light at the end of the tunnel” (P15); and “I still go out to church and a few other places but I can’t stay very long. We don’t go out very much – we go to my daughter’s for dinner and before we finish he wants to go home” (P8).

Mood Regulation

All interviewees reported that the caregiving role often negatively affected their mood and discussed the need to actively regulate their mood to maintain emotional well-being and the ability to provide optimal care for the stroke
survivor. For example: “taking care of my husband has taken a toll on me – I am more irritable than before and it has made me more anxious and nervous – I was looking forward to this part of our lives and we never expected this – it has taken away our dreams” (P7); “I often feel sad and depressed – very stressed” (P18); and “I feel negative about things and I don’t look forward to the future” (P8).

Need to master additional skills

Adopting the caregiving role required learning new skills related to both caregiving and the roles previously assumed by the individual with the stroke. This included organizing activities associated with home care, medical appointments, transportation, and finances: “Before my husband would help me with things around the house but now I must do everything on my own” (P25); “my husband used to look after the finances but now I have to do it and I don’t enjoy this and I worry a lot about this added responsibility” (P8).

Themes mapped back to the working model of emotional vitality

Four themes identified were mapped back to the working model from stage one of the concept analysis including: Impact on Physical and Emotional Well-being, Engagement in Meaningful Activity, Need to Master New Skills, and Mood Regulation. The key indexes and sub-themes that were identified did not map directly to the original model resulted in creation of a new theme called “Recognition and Support for Assuming the Caregiving Role.” Table 3.2 summarizes the results of the qualitative methods for emotional vitality concept
analysis used thus far by our group, and Figure 3.1 summarizes an overall proposed model of emotional vitality for caregivers.

Discussion

In this study, a secondary analysis was conducted on data from caregivers of stroke survivors who described the emotional consequences associated with caring for someone with a serious health condition. The results contribute additional evidence to the four domains initially identified. The analysis of the data also indicated an additional domain related to the importance of receiving recognition and support from others for assuming the caregiver role.

Taken together, these results suggest that emotional vitality is a multidimensional concept of importance to individuals interacting with health care systems. Specifically, in this study there was strong emphasis on the importance of energy and physical well-being, and mood as being the most frequently mentioned domains that impact caregiver emotional vitality. While there is likely to be considerable overlap in central domains of emotional vitality among groups, the relative weighting of each domain may differ. Further research is needed to understand if these domains are weighted more strongly throughout the continuum of the construct, or simply a prerequisite for having baseline levels of emotional vitality.

Of note, each domain identified by these caregivers in this study has relevance for the health care team members, clinical researchers and even policymakers. In treatment and care settings, each domain represents a potentially modifiable target
of assessment and intervention by health care professionals. For example, health professionals can play an active role in assessing and providing support to caregivers to help them fulfill responsibilities and persist in the caregiving role while maintaining their stamina, health and well-being. Many health professionals now receive specific training that can help them develop treatment plans that promote physical health, positive mood, mastery of new life roles and responsibilities, and achievement of life balance.

The identification of domains relevant to emotional vitality in caregivers has important implications for healthcare treatment, delivery and policy. With the population increasing in age, the number of informal caregivers in developed countries is estimated to rise by about 75% in the upcoming decade. 26 As one recent report noted “it’s not if, it’s when you will become a caregiver.”24 The deinstitutionalization of care for individuals with chronic health conditions commands a much closer examination of the needs of this group. The model for emotional vitality offers an initial platform to understand the complexity of the needs of caregivers and how to begin assessing and targeting them. The domains in this model also reflect priority areas outlined in recent calls of support for family caregivers. 9,16,17,24,26,27,141,142,149 These reports highlight that successful caregiving is about much more than acquiring health information about the condition of a loved one. Previous caregiver research has focused on minimizing “strain” or “burden”, often outlining methods to minimize burnout and disability. This model suggests that emotional vitality, in the context of the caregiving experience, is a comprehensive concept that health care professionals can
approach from an angle of optimizing “capability” and well-being. Empowering care providers by enhancing emotional vitality may facilitate successful adaptation of individuals living with chronic health conditions and the retention of satisfied family members in the caregiving role. In order to do so, future work is needed to develop strategies for identifying those at risk for suboptimal coping, targeted interventions to empower caregivers, and ensuring support is in place to allow caregiver support services are integrated into current best care practices of all health care professionals.

Although the research interests of this project differed from the original study for which the data was originally collected, the richness of the available data allowed for the pursuit of information distinct from the original work. The secondary analysis provided a starting point to understand emotional vitality from the perspective of individuals who have experienced a catalytic event in their lives that draws directly from the concept under investigation.

**Limitations of the Research**

Regarding the limitations of this study, secondary analysis of the qualitative interviews of caregivers introduced inherent bias into this study. Although this archived data provided rich material to be re-analyzed and compared with the contemporary data from our first study, this did not dissolve the problem of context in which this data was originally collected. This may have introduced bias into this study as our topic was not the direct focus of the earlier study. The context, while similar to many North American cities, may have provided unique
information, specific to caregivers in a particular area in Canada. Results may not be applicable to caregivers in other settings who do not always have access to a basic level of medical care. Caregivers in this study were mostly spouses or adult children and it is unclear whether these results are applicable to caregivers of children, teens or even adult children. In order to have a greater consensus on the relevant domains of emotional vitality in relation to other types of caregivers, more research is needed to identify the common characteristics and specific attributes of emotional vitality relative to this population and other subgroups of caregivers.

Conclusion

The emotional journey of caregiving is complex and dynamic. Methods to support the maintenance of emotional vitality while balancing the responsibility and stress associated with caregiving are unknown. Health professionals, who may have ongoing contact with this vulnerable population, can play an important role by identifying those at risk for diminished emotional vitality. This construct of caregiver emotional vitality provides a starting point that can be used to guide assessment and intervention strategies, with five specific areas of emphasis on physical well-being and health, mood, sense of control/mastery of new skills, engagement in meaningful activity, and support from others. The identification of these domains can facilitate research to understand how best to support the invisible backbone of our health care system.
<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes*</th>
<th>Indexes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Energy and Physical Well-being</td>
<td>Pain (n=4)</td>
<td>Headaches</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Muscle pain</td>
</tr>
<tr>
<td></td>
<td>Fatigue (n=14)</td>
<td>Tired all the time</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No energy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No pep</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sleep problems</td>
</tr>
<tr>
<td></td>
<td>Other physical (n=11)</td>
<td>Weak/No strength</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dizzy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>High blood pressure</td>
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<tr>
<td></td>
<td></td>
<td>Sick frequently</td>
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<tr>
<td></td>
<td></td>
<td>Weight loss/gain</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Psoriasis</td>
</tr>
<tr>
<td>Regulation of Mood</td>
<td>Depressed (n=6)</td>
<td>Negative about everything</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hopeless/Does not look forward to the future</td>
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<tr>
<td></td>
<td></td>
<td>Sad</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Apathetic</td>
</tr>
<tr>
<td></td>
<td>Anxious (n=16)</td>
<td>Worry constantly</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Overwhelmed</td>
</tr>
<tr>
<td></td>
<td>Irritability (n=7)</td>
<td>Frequent displays of temper</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Resentful</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Impatient</td>
</tr>
<tr>
<td>Engagement in Meaningful Activity</td>
<td>Effect on Social life (n=21)</td>
<td>No time to see friends</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Too tired to visit with friends</td>
</tr>
<tr>
<td></td>
<td>Effect on Employment (n=6)</td>
<td>No time</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cannot concentrate on both work and caregiving</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Constant worry</td>
</tr>
<tr>
<td></td>
<td>Getting out of the house (n=11)</td>
<td>No time</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Spouse worried</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Too many things to do for loved one</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Loved one tires too easily</td>
</tr>
<tr>
<td>Sense of Control/Mastery of new skills</td>
<td>Completing all tasks (n=21)</td>
<td>Completing care for stroke survivor</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Completing home maintenance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ability to achieve life balance</td>
</tr>
<tr>
<td></td>
<td>Taking on both roles (n=2)</td>
<td>Learning to assume new roles</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Learning the roles previously assumed by the stroke survivor.</td>
</tr>
<tr>
<td></td>
<td>Knowledge (n=3)</td>
<td>Illness-specific</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Health care system access</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Self-care</td>
</tr>
<tr>
<td>Support from others</td>
<td>Family (n=12)</td>
<td>Emotional support</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Patience</td>
</tr>
<tr>
<td></td>
<td>Provision of respite</td>
<td></td>
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<tr>
<td>-----------------------------------</td>
<td>---------------------------------------------</td>
<td></td>
</tr>
<tr>
<td><strong>Friends (n=5)</strong></td>
<td>Outlet to get out for short period</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Provision of emotional support</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Source of laughter</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Help with errands/chores</td>
<td></td>
</tr>
<tr>
<td><strong>Healthcare professionals (n=23)</strong></td>
<td>Enough support and resources</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Organized and accessible</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Consistent follow-up/care</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Respite</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Emotional support</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Long-term Follow-up</td>
<td></td>
</tr>
</tbody>
</table>

* Number of caregivers who reported sub-theme in secondary analysis
### Table 3.2 Domains that emerged from each step of the content analysis for emotional vitality

<table>
<thead>
<tr>
<th>Content Analysis</th>
<th>Physical Well-being</th>
<th>Energy</th>
<th>Mood</th>
<th>Engagement</th>
<th>Mastery</th>
<th>Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scoping Review (n=10 studies)</td>
<td>✓</td>
<td></td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dephi Mapping (n=25 health professionals)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Caregiver analysis (n=30 caregivers)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Overall</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>
**Figure 3.1** Theoretical model of emotional vitality generated from caregiver interviews

- Physical health and well-being
- Engagement in meaningful activity
- Regulation of mood
- Sense of control/mastery of new skills
- Support & recognition from others
CHAPTER 4: Manuscript 3. The role of Rasch analysis in concept exploration: the case for emotional vitality in caregivers

Preface to Manuscript 3

Initial steps of a content analysis\textsuperscript{144} were performed in the two previous studies to develop a working theoretical model for emotional vitality in individuals with chronic health conditions and the caregivers who support them. The process of initial inquiry included a scoping review of the literature (n=10 studies), Delphi mapping exercise using the International Classification of Functioning, Disability, and Health\textsuperscript{1} (n=25 health care professionals), and a secondary analysis of interviews of caregivers of stroke survivors (n=30). The results of this preliminary work contributed evidence towards the conceptualization of emotional vitality in the caregiver population, specifically describing five internal components including: (1) physical health well-being, (2) regulation of mood, (3) sense of control/mastery of new skills, (4) engagement in other roles and activities, and (5) support and recognition from others. The next step in the content analysis was to use quantitative methods to validate and refine the concept in the caregiver population. The aim was to use the results as a blueprint guide to inform a future measurement strategy to capture emotional vitality in caregivers of stroke survivors.

The purpose of this study was to add to the conceptualization of the emotional vitality construct by contributing evidence that the domains within emotional vitality map onto a unidimensional hierarchy and cover a continuum from low to high. For this Rasch analysis was used.
Title: The role of Rasch analysis in concept exploration: the case for emotional vitality in caregivers

For submission to: Archives of Physical Medicine and Rehabilitation

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Keywords: Measurement, Rasch, emotional vitality, caregiver
ABSTRACT

Objective: To estimate the extent to which items fitting one or more aspects of emotional vitality in caregivers of people with stroke relate to an underlying theoretical and hierarchical construct.

Design: Secondary analysis of longitudinal caregiver data (n=409). Rasch analysis was used as a method of concept analysis to quantitatively support the validity of a previously developed working theoretical model of emotional vitality in stroke caregivers.

Setting: N/A

Participants: Caregiver of stroke survivors followed for one year post stroke.

Intervention: not applicable.

Main Outcome Measure: not applicable.

Results: 23 items quantitatively represented the structure of the emotional vitality construct in the population under investigation. Items fit together uniformly to reflect a unidimensional concept covering the full statistical range of emotional vitality of caregivers of stroke survivors; however, global fit of the Rasch model was not achieved longitudinally, and all items did not meet the fit criteria of the Rasch model. Information specific to the ordering of response categories, individual and item fit, as well as targeting of these items to the sample were revealed.
Conclusion: This study contributed evidence to the existence of five domains in the working theoretical model of emotional vitality. The results give insight into how future measures of the concept can take place by carefully selected items that reflect the concept under investigation, possess appropriate response categories for caregivers, and reflect the full range of the emotional vitality concept for the target population.

Keywords: Measurement, Rasch, Emotions, Caregiver

Abbreviations: ICF (International Classification of Functioning, Disability, and Health); RMT (Rasch Measurement Theory)
INTRODUCTION

Family caregivers of individuals with chronic health conditions are key stakeholders in the support of the current health care system.\textsuperscript{140,151,152} Caregivers of stroke survivors are primary examples of individuals who play important and sizable roles in the complex care of individuals living in the community. Over 80 percent of caregiving responsibilities of community-dwelling stroke survivors are performed by a family member, making this group the true front line providers of care for this population.\textsuperscript{27} In addition to a sudden change in lifestyle and role loss, the work requires an immense investment of both physical and emotional resources. To date, there is no clear evidence about how best to support caregivers of stroke survivors beyond the provision of information and advice regarding best care to the stroke survivor.\textsuperscript{153} What is known is that caregivers report sub-optimal levels of stress, anxiety, depression, social isolation, and quality of life compared to non-caregivers.\textsuperscript{12,13,21} Careful attention to the emotional well-being of this group is essential to ensure that they can continue to meet the physical and emotional needs of the stroke survivor without incurring significant cost to their own health or quality of life.

Emotional vitality is an emerging concept that describes an individual’s overall level of emotional functioning. In two previous studies,\textsuperscript{145} initial steps of a content analysis\textsuperscript{144} were performed to develop a working theoretical model for emotional vitality in individuals with chronic health conditions and the caregivers who support them. The process of initial inquiry included a scoping review of the literature (n=10 studies), Delphi mapping exercise using the International
Classification of Functioning, Disability, and Health¹ (n=25 health care professionals), and a secondary analysis of interviews of caregivers of stroke survivors (n=30). The results of this preliminary work contributed evidence towards the conceptualization of emotional vitality in the caregiver population, specifically describing five internal components including: (1) physical health well-being, (2) regulation of mood, (3) sense of control/mastery of new skills, (4) engagement in other roles and activities, and (5) support and recognition from others. The next step in the content analysis is to use quantitative methods to validate and refine the concept in the caregiver population. This will lead to a blueprint guide to inform a future measurement strategy to capture emotional vitality in caregivers of stroke survivors.

Traditional statistical techniques for quantitative concept analysis include factor analysis, Cronbach’s Alpha¹⁵⁴, and correlation.¹⁴⁴ These techniques are useful and may reveal whether or not a measurement model based on the theoretical conceptualization fits data. These techniques are limited in that they offer only descriptive information about whether or not the original conceptualization should be put into question.¹⁴⁴ Rasch Measurement Theory (RMT) proposes a method to evaluate how observed data (for example, caregiver responses to a set of items) are concurrent with “fit” predictions of how items should perform to generate reliable and valid measurements of a concept under investigation. This mathematical way of aligning items onto a linear continuum was developed by the late George Rasch, a Danish mathematician.¹⁵⁵ He identified that responses to questions could be tested against a theoretical hierarchal model (now known as
the Rasch model) using a logistic function. The result of the analysis fitting the item responses to the model creates an interval-level score reflecting both the difficulty of the item and the ability of a person. Particular features of the model are that estimates of person ability can be derived independently from the item difficulty, resulting in a scale score that is interpretable across persons and over time, because the score does not depend on whether more difficult or easier items were administered.\textsuperscript{65,92}

The aim of this study was to add to the conceptualization of the emotional vitality construct by contributing evidence that the domains within emotional vitality map onto a unidimensional hierarchy and cover a continuum from low to high. More specially, the purpose of this study was to estimate the extent to which items fitting one or more aspects of emotional vitality in caregivers of people with stroke relate to an underlying theoretical and hierarchical construct.

**METHODS**

Data for this study came from a Canadian study: \textit{“Understanding Health Related Quality of Life Post-Stroke: A Study of Individuals and Their Caregivers.”} The methods for this study have been described previously.\textsuperscript{156} Briefly, a longitudinal study of an inception cohort was carried out evaluating persons with stroke and their caregivers within 10 days of stroke, and then at 1, 3, 6, and 12 months post-stroke. Caregivers answered questions related to health-related quality of life, disability, and physical and emotional well-being at 1, 3, 6, and 12 months post-
stroke. This provided the set of items to measure emotional vitality across a spectrum of young (19 years old) to very old adults (93 years old). See Table 4.1 for baseline characteristics of the sample. The original study received approval from the McGill University Institutional Review Board and from the Research Ethics committees of all participating hospitals.

**Item generation**

The working model of emotional vitality was used to select items for secondary analysis that theoretically tapped into the construct under investigation. A total of 107 items (of a possible 193) were identified from several indices commonly used to measure quality of life, mood, mastery, and participation. These items came from the following indices: RAND-36,\(^{157}\) Positive and Negative Affect Scale,\(^{158}\) Center for Epidemiological Depression Scale,\(^{80}\) EQ-5D,\(^{159}\) Personal Mastery Scale,\(^{63}\) and the Caregiver Quality of Life Scale.\(^{160}\) The indices represent one or several aspects of the construct. Also available were variables that could inform how items behave for people with different characteristics. There variables were sex, age, education, and support from children.

**Data Analysis**

Data from subjects’ ratings on ability on 107 items over four points in time were available for analysis. Rasch analysis was conducted to estimate the extent to which each item fit the underlying theoretical continuum. The following criteria for Rasch model fit were: (i) threshold ordering, (ii) item fit, (iii) invariance, (iv) unidimensionality, and (v) appropriate targeting. All assumptions were verified using the Masters’ Partial Credit model,\(^{161}\) an appropriate mathematical derivation
of the Rasch model suitable for investigating items with ordinal response options.

All analyses were performed using RUMM 2030.\(^{162}\)

\(\text{(i) Threshold Ordering}\)

First, statistical and graphical inspection of threshold locations and plots was performed in order to estimate the extent to which the ordering of thresholds was as expected. In the presence of disordered thresholds, response categories were collapsed.

\(\text{(ii) Item Deletion based on fit and local dependence}\)

After rescoring the disordered thresholds, items were considered for deletion based on observation of item fit residuals outside of \(\pm 2.5\), significant chi-square value \((p<0.05)\), and standardized local dependence of greater than 0.3 with other items. Because the items tested for fit to the Rasch model came from a wide variety of indices, item misfit was expected. Items were removed iteratively, starting with those with the items with the worst fit residual statistics. Item fit and local dependence were re-examined after each deletion. This process was replicated until global fit was achieved with Bonferroni correction of \(p>0.01\) for multiple items and global fit to the model resulted in an item-trait global \(\chi^2\) of greater than 0.05.

\(\text{(iii) Differential Item Functioning}\)

Once global fit to the model was achieved, differential item functioning was examined for gender, education, presence of children, and time of assessment. Specifically, item characteristic curves were examined for each item by group and a two-way analysis of variance with a Bonferroni correction with a probability base of 0.05 was used to determine whether each items’ location was stable across
groups. Finally, a Kruskall-Wallis rank test was performed to test if the ordering of items in terms of difficulty was different for time of assessment.

(iv) Unidimensionality

Examination of the scale’s ability to measure a single construct using a principal components analysis (PCA) of the residuals was performed to test the presence of a pattern of the residuals grouping into more than one subscale once the “Rasch factor” was extracted. The hypothesis of this PCA was that the response structure was unidimensional and that, apart from a single variable and the item parameters mapped on this variable, the remaining variation was random. Depending on the factor loadings resulting from the PCA, a paired t-test was performed to test whether person estimates derived from the subtests of items were significantly different from each other. Evidence for unidimensionality was provided if less than 5% of the t-tests were significant.

(v) Targeting

Rasch analysis was used to verify if the items were appropriate for, or well targeted for the caregiver sample being measured. Assessment of targeting was achieved by an examination of the spread of person and item locations in the relative distributions of the these two parameter estimates.\textsuperscript{163} Optimal targeting was gauged by how closely the sample’s average measure of emotional vitality approached “zero”, the average item difficulty.\textsuperscript{84}

(vi) Content validity

The items remaining after best fit was achieved were mapped to the working model of emotional vitality to reflect an ordered hierarchy of the construct.
RESULTS

Data Structure and Item Reduction

Disordered thresholds were observed and rescored for 88 of the 107 items. In most cases (n=65), participants were only able to discern two response levels. After rescoring all disordered items, 64 items were removed iteratively based on model fit criteria, and a further 20 items were removed for reasons of local dependence with other items. “Best” fit of the data to the model, but not ideal fit, (p>0.05) was achieved with 23 items. Any item, or combination of items removed after this point resulted in a drastic increase in the item-trait interaction chi-square. The global statistics for the best fitting model with the 23 items were an item-trait interaction chi-square of 495 (df:207, p<0.01), and person and item fit residuals of -1.08 (SD=4.63) and -0.76 (SD=2.31) respectively. Although model fit was not achieved with all times included, overall model fit with the 23 items was achieved when the data were examined cross-sectionally at each time point. See Table 4.2 for a summary of the global statistics for each Rasch model at the four points in time. Table 4.3 shows the characteristics of the 23 items that fit “best” to the Rasch model. With a Bonferroni correction to the Chi-Square item probability, 17/23 items are shown to fit the model. Further, 19/23 residuals are within the range of ±2.5. The fit residuals of 1193/1196 participants met the critical value of ±2.5.
Differential Item Functioning

Examination of both graphical and statistical evidence showed the difficulty level of the items was uniform across sex, education, children, and time. Results from the Kruskall-Wallis test suggest the probability of the differences in rank between time points was greater than or equal to 0.39 for all 23 item. However, visual inspection of rank order of the items highlights three items that change more than 2 positions in rank in the item hierarchy across time. Table 4.4 summarizes the rank order across time and highlights the three items of potential concern.

Unidimensionality

Examination of the Eigenvalues from the principal component analysis suggested evidence that the response structure of the 23 items was potentially comprised of two or more subscales. This was also supported by the loadings in the first principal component that showed clear patterns of residuals on successive components, with 5 items with large positive correlations, and 10 others with negative loadings. However, evidence from the t-test grouping these items together in subtests revealed that the amount of multi-dimensionality that was present was minimal, with none of the participants showing significant differences between the two subtests (t=-7.77, p<0.01). See Table 4.5 for principal components summary.

Targeting

The structure of distribution of persons and items across the measure of emotional vitality is depicted in Figure 4.1. The horizontal axes, scaled in logits, denote the
level of emotional vitality going from lowest to highest. In the upper half of the vertical axis, the proportion of participants is represented, whereas the lower half is represented by the number of items. Each pink and blue bar represents the frequency distribution of subjects and items respectively at each location. The item locations ranged from -4.78 (SE:0.32) to +2.21 (SE:0.05) logits, with a mean location of 0.00 (SE:1.65). The measure of person ability ranged from -5.49 (SE:1.24) to +2.2 logits (SE:0.05) with a mean location of -1.54 (SE:1.13).

Content Mapped to EV model

The best fitting Rasch model resulted in 23 items being mapped back to the components of the conceptual model. Eight items mapped back to “physical energy and well-being”, 7 items mapped to “mood”, 3 items for both “mastery” and “support”, and only 2 items mapped back to the “engagement in meaningful activity” component. Items in the first two components covered the range of the construct, whereby items for mastery, support, and engagement in meaningful activity covered only the lower end of the hierarchy of the construct. See Figure 4.2 for depiction of how items mapped back to the Emotional Vitality model and their respective item hierarchy under each component of the model.

DISCUSSION

In this study, Rasch analysis was used as a method of concept analysis to quantitatively support the validity of our working theoretical model of emotional vitality in caregivers of stroke survivors. Rasch analysis afforded an in-depth view of how items were mapped back to this model of emotional vitality, specifically
showing how 23 items quantitatively represented the structure of the concept in
the population under investigation. Rasch analysis also provided information
specific to the ordering of response categories, individual and item fit, as well as
illustrating the hierarchical ordering of items and the targeting of these items to
the sample. Specifically, Rasch showed that items fit together uniformly to reflect
a unidimensional concept covering the full range of emotional vitality of
caregivers of stroke survivors. The longitudinal comparison between item rank
and participant ability showed that the items were stable across time and there was
not enough evidence to suggest that the items or participants experienced response
shift in the first year of caregiving.\textsuperscript{156}

The study results suggest several reasons why this preliminary group of items
reflects emotional vitality. First, the data set is unique in that it is the largest data
set on caregivers of people with stroke amassed today, and data were collected
longitudinally, at four points in time. The caregiving experience was one of the
primary motivations for mounting the study and thus a rich portfolio of measures
was available, reflecting the conceptualization of the caregiving experience at that
time (circa 2000). A key strength is that the data were already in hand and for the
purposes of concept development, this is an ethical and efficient way of
identifying how future primary data collection could further advance the field.
Items for the Rasch analysis were selected from this database because they
mapped to a construct that emerged from the literature, from mapping to known
factors that are important to emotion and vitality and from interviews with
caregivers of persons with stroke talking about their caregiving experience. We
used all items that potentially measured any aspect of our working conceptual model of the construct, resulting in a rich item bank of 107 items available for Rasch analysis. Items that were included in the final model mapped back to all five domains of our working model that resulted in the initial stages of the content analysis previous to this study. The number of items that loaded to each domain supported the results of the qualitative interviews of caregivers which suggested that the five domains in question were not equally recognized. In this study, more items mapped back to two domains: (i) physical well-being and energy, and (ii) mood, supporting the previous findings from our qualitative work that emphasized these two areas as the most important contributors to overall emotional vitality.

Two violations to the Rasch model were observed: (1) global fit of the Rasch model was only achieved cross-sectionally, and (2) all items did not meet the three fit criteria of the Rasch model: (i) residuals did not fall within ±2.5 (5 items), (ii) significant chi-square value (p<0.05) (6 items), and (iii) standardized local dependence of greater than 0.3 with other items (2 items). “Best” fit was not achieved; however, key pieces of information resulting from the Rasch analysis potentially explain the anomalies and offer an understanding about how best to advance the development of the construct quantitatively. For example, it is recognized that the power to detect misfit using the chi-square statistic depends on sample size. The misfit of the Rasch model longitudinally may be the result of a large sample size and power so great that misfit of many items occurred, even when the observed and expected values were very close. In our study, as the sample size decreased, the patterns of misfit improved. Therefore, future work to
understand the fit of the Rasch model to this data should take sample size into consideration.

Another key piece of information was revealed through the examination of the thresholds of the items included in the analysis. Beyond the interpretation of the residual fit statistic, caregivers’ inability to discriminate between multiple response options on several items was noted. Of the 23 items included in the final model, 18 were rescored, 10 of which were rescored as binary. Based on the individual item fit residual statistics and threshold probability curves alone, enough evidence existed to support collapsing response categories for the items in this analysis. However future work for selecting items to measure emotional vitality should carefully consider the number of response options appropriate for caregivers to answer questions with the greatest precision and least amount of bias possible. It is possible that the caregivers in this study were unable to discriminate between multiple response options, or that the response category labelling was problematic. As ordered thresholds are fundamental to establishing the validity of a measurement scale, in developing a future measure of emotional vitality, careful consideration of the observed patterns of response by caregivers on each item should take place.

It is important to note that the results of this study do not suggest an “item bank” or “measure” of emotional vitality. This study was an exercise in statistical modelling, rather than an attempt to develop a measurement strategy to capture emotional vitality. It is recognized that in order for models to be independent of any data set, data should be valid in content and fit the underpinnings of the
theoretical model under investigation.\textsuperscript{92,166,167} Therefore, in future work to develop a measure of emotionally vitality, selection of items should be based not only on our theoretical model, but also on a hypothesized theory of hierarchy of the items, their capacity to span the range of the construct in the caregiver population, and their ability to reflect response options that can match caregiver ability to discriminate between categories. The results summarize fit of the Rasch model to our data. Without a-priori hypotheses about item hierarchy, this may have simply led to a \textit{model fitting data} by chance, rather than \textit{data fitting our theoretical model}. An example of this is how two items from the EQ-5D (related to pain and mobility) were included in this Rasch model. Upon reflection, these items appear to reflect the physical consequences of being a caregiver of a stroke survivor, rather than a component of the “energy and physical well-being” domain that was described in the previous qualitative work in this concept analysis. With respect to the understanding that continuous quantity is contingent upon substantive theory and empirical demonstrations to capture a concept quantitatively,\textsuperscript{92,168} future concept analysis work should carefully consider the items that reflect the components of the emotional vitality construct, a clear hypothesis about their relationships to each other, and a hypothesis for how they capture the full range of the construct across the population under study. This Rasch analysis has allowed for a deep understanding the behavior of all 107 items across time in the caregiving population. Further, it has provided quantitative evidence for the concept under investigation and furthers the process of inquiry that explores emotional vitality as a concept of importance for health research and practice. The refinement of concepts using Rasch analysis as a quantitative
method is unique to this study and the results are valuable for future measurement and instrument development. In reference to Morse’s steps of concept inquiry, the results of this study provide additional evidence towards the concept analysis about identification of the emotional vitality as a concept of importance for caregivers, its development, and the domains which are uniformly linked together. This study, in support of the two previous studies (Manuscripts 1 and 2), suggests that there is now enough evidence to further test this well-developed concept and its dimensions. In order to do so, future work is now needed to develop a measurement strategy to capture emotional vitality and test the validity of the conceptualization across populations of caregivers and in different caregiving contexts.

It has been argued that the most important problem facing the scientific measurement of psychological systems is the lack of descriptive theories of human behavior. This study, in addition to previous work completed, has allowed for critical assessment of the concept of emotional vitality. In what might be referred to as a “pre-paradigmatic phase in scientific development”, this has been essential to develop a strong foundation from which a measurement strategy to capture emotional vitality can be guided. Further, a strong understanding of the concept will facilitate communication of future research findings to both the scientific community and to rehabilitation practitioners. At this stage of the concept development, it was appropriate to use only statistically guided methods to understand how these items behaved amongst each other and mapped back to our working model of emotional vitality. Rasch analysis, based on a strong
measurement theory\textsuperscript{86,87,164}, afforded the opportunity to understand not only which items mapped back to our theoretical model of emotional vitality, but also information about item response categories, misfit, and targeting of these items to this populations. This information, alongside our previous qualitative work to define and describe the domains of emotional vitality in caregivers of stroke survivors, provides a working conceptual model that can be used for identification of those variables relevant for measurement of emotional vitality. Future validation of the model, or possible refinement of the original conceptualization, can take place once an instrument to measure emotional vitality is developed and tested psychometrically.

\textbf{CONCLUSION}

In summary, this paper presents the results of the first quantitative step to understand how emotional vitality manifests itself in caregivers of stroke survivors. Rasch analysis contributed evidence to the existence of five domains in the working theoretical model of emotional vitality. In addition, the results give insight into how future measures of the concept can take place by carefully selecting items that reflect the concept under investigation, possess appropriate response categories for caregivers, and reflect the full range of the emotional vitality concept for the target population. Emotional vitality may be a concept within the grasp and control of caregivers of stroke survivors. Before it becomes a valuable target for psychosocial and rehabilitative interventions, future development of a measurement model for emotional vitality is needed to help
identify areas where interventions can be offered to support this vulnerable population.
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Women N(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Women</strong></td>
<td>284 (69.4)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>mean years (SD)</td>
<td>58.4 (14.9)</td>
</tr>
<tr>
<td>18-40 years N(%)</td>
<td>56 (13.8)</td>
</tr>
<tr>
<td>41-55 years N(%)</td>
<td>130 (31.7)</td>
</tr>
<tr>
<td>56-70 years N(%)</td>
<td>134 (32.7)</td>
</tr>
<tr>
<td>71+ years N(%)</td>
<td>89 (21.8)</td>
</tr>
<tr>
<td><strong>Live with Stroke Survivor (% yes)</strong></td>
<td>84.3</td>
</tr>
<tr>
<td><strong>Have Children (% Yes)</strong></td>
<td>80.8</td>
</tr>
<tr>
<td><strong>Employed (% Yes full or part time)</strong></td>
<td>33.7</td>
</tr>
<tr>
<td><strong>Education (%)</strong></td>
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</tr>
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<td>High School or Less</td>
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<tr>
<td>Some College</td>
<td>7.0</td>
</tr>
<tr>
<td>Completed College</td>
<td>10.5</td>
</tr>
<tr>
<td>Some University</td>
<td>9.4</td>
</tr>
<tr>
<td>Completed University</td>
<td>7.0</td>
</tr>
<tr>
<td>Completed Post graduate</td>
<td>13.1</td>
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</tbody>
</table>

Table 4.1 Baseline Characteristics of Caregiver Sample (n=409)
Table 4.2 Summary of Global Fit Statistics for the Rasch Models

<table>
<thead>
<tr>
<th>ITEM-TRAIT INTERACTION</th>
<th>Full 107 item model (n=1196)</th>
<th>23-item model (n=1196)</th>
<th>Model at time 1 (n=343)</th>
<th>Model at time 2 (n=309)</th>
<th>Model at time 3 (n=280)</th>
<th>Model at time 4 (n=264)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Item Chi-Square</td>
<td>17,267.32 ±0.85</td>
<td>495.11 ±1.65</td>
<td>203.72 ±1.54</td>
<td>254.90 ±1.78</td>
<td>235.28 ±1.18</td>
<td>239.59 ±1.79</td>
</tr>
<tr>
<td>Total Deg of Freedom</td>
<td>963</td>
<td>207 ±1.99</td>
<td>207 ±1.01</td>
<td>207 ±1.09</td>
<td>207 ±1.36</td>
<td>207 ±1.24</td>
</tr>
<tr>
<td>Total Chi-Square Probability</td>
<td>0.00000 ±0.20</td>
<td>0.55 ±0.63</td>
<td>0.14 ±0.66</td>
<td>0.09 ±0.44</td>
<td>0.06 ±0.82</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ITEM-PERSON INTERACTION ITEM</th>
<th>Difficulty</th>
<th>Fit Residual</th>
<th>Measure</th>
<th>Fit Residual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full 107 item model (n=1196)</td>
<td>0.00 ±0.85</td>
<td>-1.08 ±4.63</td>
<td>-0.04 ±0.20</td>
<td>-0.76 ±2.31</td>
</tr>
<tr>
<td>23-item model (n=1196)</td>
<td>0.00 ±1.54</td>
<td>-0.57 ±1.99</td>
<td>-1.54 ±1.13</td>
<td>-0.23 ±0.67</td>
</tr>
<tr>
<td>Model at time 1 (n=343)</td>
<td>0.00 ±1.78</td>
<td>-1.41 ±1.08</td>
<td>-1.41 ±1.08</td>
<td>-0.19 ±0.63</td>
</tr>
<tr>
<td>Model at time 2 (n=309)</td>
<td>0.00 ±1.80</td>
<td>-0.28 ±1.09</td>
<td>-1.55 ±1.09</td>
<td>-0.21 ±0.66</td>
</tr>
<tr>
<td>Model at time 3 (n=280)</td>
<td>0.00 ±1.18</td>
<td>-0.34 ±1.36</td>
<td>-1.64 ±1.13</td>
<td>-0.15 ±0.44</td>
</tr>
<tr>
<td>Model at time 4 (n=264)</td>
<td>0.00 ±1.79</td>
<td>-0.36 ±1.24</td>
<td>-1.80 ±1.28</td>
<td>-0.32 ±0.82</td>
</tr>
</tbody>
</table>
Table 4.3 Characteristics of the items mapped to the concept of emotional vitality using Rasch Analysis

<table>
<thead>
<tr>
<th>Index</th>
<th>Item</th>
<th>Component</th>
<th>Difficulty</th>
<th>SE</th>
<th>Fit residual</th>
<th>$\chi^2$</th>
<th>F-Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>RAND-36</td>
<td>9h</td>
<td>Mood</td>
<td>-2.21</td>
<td>0.05</td>
<td>-1.77</td>
<td>12.11</td>
<td>1.50</td>
</tr>
<tr>
<td>CES-D</td>
<td>11</td>
<td>Energy/WB</td>
<td>-1.77</td>
<td>0.06</td>
<td>0.13</td>
<td>14.84</td>
<td>1.56</td>
</tr>
<tr>
<td>RAND-36</td>
<td>9a</td>
<td>Energy/WB</td>
<td>-1.55</td>
<td>0.05</td>
<td>-3.98</td>
<td>40.77</td>
<td>5.67</td>
</tr>
<tr>
<td>Cg QOL</td>
<td>VAS</td>
<td>Energy/WB</td>
<td>-1.42</td>
<td>0.04</td>
<td>3.13</td>
<td>33.59</td>
<td>3.33</td>
</tr>
<tr>
<td>RAND-36</td>
<td>9i</td>
<td>Energy/WB</td>
<td>-1.34</td>
<td>0.03</td>
<td>2.50</td>
<td>43.20</td>
<td>4.45</td>
</tr>
<tr>
<td>Mastery Scale</td>
<td>1</td>
<td>Mastery</td>
<td>-1.15</td>
<td>0.04</td>
<td>4.31</td>
<td>50.79</td>
<td>4.67</td>
</tr>
<tr>
<td>CgQOL</td>
<td>33</td>
<td>Energy/WB</td>
<td>-1.10</td>
<td>0.05</td>
<td>0.80</td>
<td>23.80</td>
<td>2.64</td>
</tr>
<tr>
<td>CIS</td>
<td>10</td>
<td>Support</td>
<td>-0.71</td>
<td>0.04</td>
<td>-0.59</td>
<td>6.68</td>
<td>0.78</td>
</tr>
<tr>
<td>CES-D</td>
<td>1</td>
<td>Mood</td>
<td>-0.67</td>
<td>0.06</td>
<td>-1.45</td>
<td>26.07</td>
<td>3.20</td>
</tr>
<tr>
<td>CES-D</td>
<td>5</td>
<td>Mood</td>
<td>-0.63</td>
<td>0.06</td>
<td>-2.34</td>
<td>29.21</td>
<td>3.81</td>
</tr>
<tr>
<td>Mastery Scale</td>
<td>5</td>
<td>Mastery</td>
<td>-0.53</td>
<td>0.05</td>
<td>-0.65</td>
<td>6.77</td>
<td>0.80</td>
</tr>
<tr>
<td>CES-D</td>
<td>20</td>
<td>Energy/WB</td>
<td>-0.50</td>
<td>0.07</td>
<td>-3.91</td>
<td>46.68</td>
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<tr>
<td>Mastery Scale</td>
<td>2</td>
<td>Mastery</td>
<td>-0.49</td>
<td>0.05</td>
<td>1.51</td>
<td>14.62</td>
<td>1.61</td>
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<tr>
<td>CES-D</td>
<td>10</td>
<td>Mood</td>
<td>-0.26</td>
<td>0.07</td>
<td>-0.02</td>
<td>8.83</td>
<td>0.88</td>
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<tr>
<td>CES-D</td>
<td>17</td>
<td>Mood</td>
<td>0.38</td>
<td>0.08</td>
<td>1.15</td>
<td>13.76</td>
<td>1.69</td>
</tr>
<tr>
<td>CES-D</td>
<td>13</td>
<td>Mood</td>
<td>0.19</td>
<td>0.08</td>
<td>-0.73</td>
<td>10.54</td>
<td>1.19</td>
</tr>
<tr>
<td>EQ-5D</td>
<td>Pain</td>
<td>Energy/WB</td>
<td>0.26</td>
<td>0.06</td>
<td>-0.64</td>
<td>11.42</td>
<td>1.22</td>
</tr>
<tr>
<td>CES-D</td>
<td>9</td>
<td>Mastery</td>
<td>1.10</td>
<td>0.10</td>
<td>-0.35</td>
<td>30.66</td>
<td>3.74</td>
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<tr>
<td>CES-D</td>
<td>15</td>
<td>Support</td>
<td>1.51</td>
<td>0.11</td>
<td>-1.13</td>
<td>8.67</td>
<td>1.07</td>
</tr>
<tr>
<td>CES-D</td>
<td>19</td>
<td>Support</td>
<td>1.63</td>
<td>0.12</td>
<td>-0.61</td>
<td>11.46</td>
<td>1.34</td>
</tr>
<tr>
<td>EQ-5D</td>
<td>Usual activities</td>
<td>Activity</td>
<td>2.18</td>
<td>0.09</td>
<td>-2.05</td>
<td>19.58</td>
<td>2.71</td>
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<tr>
<td>EQ-5D</td>
<td>Mobility</td>
<td>Energy</td>
<td>2.62</td>
<td>0.09</td>
<td>-1.79</td>
<td>16.22</td>
<td>2.08</td>
</tr>
<tr>
<td>EQ-5D</td>
<td>Self-care</td>
<td>Activity</td>
<td>4.70</td>
<td>0.32</td>
<td>-1.31</td>
<td>15.71</td>
<td>3.33</td>
</tr>
</tbody>
</table>

*Items are listed in order of difficulty*
Table 4.4. Characteristics of the items mapped to the concept of emotional vitality using Rasch Analysis

<table>
<thead>
<tr>
<th>Index</th>
<th>Item</th>
<th>Component</th>
<th>All time points</th>
<th>Time 1</th>
<th>Time 2</th>
<th>Time 3</th>
<th>Time 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>RAND-36</td>
<td>9h</td>
<td>Mood</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>CES-D</td>
<td>Ce11</td>
<td>Energy/WB</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>RAND-36</td>
<td>9a</td>
<td>Energy/WB</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Cg QOL</td>
<td>VAS</td>
<td>Energy/WB</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>RAND-36</td>
<td>9i</td>
<td>Energy/WB</td>
<td>5</td>
<td>4</td>
<td>5</td>
<td>5</td>
<td>7</td>
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<tr>
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<td>6</td>
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<td>6</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>CgQOL</td>
<td>33</td>
<td>Energy/WB</td>
<td>7</td>
<td>7</td>
<td>7</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>CIS</td>
<td>10</td>
<td>Support</td>
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<td>10</td>
<td>10</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td>CES-D</td>
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<td>Mood</td>
<td>9</td>
<td>8</td>
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<tr>
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<td>Mood</td>
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<td>Mastery Scale</td>
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<td>11</td>
<td>11</td>
<td>8</td>
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<td>12</td>
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<td>10</td>
<td>11</td>
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<td>12</td>
<td>12</td>
<td>13</td>
</tr>
<tr>
<td>CES-D</td>
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<td>Mood</td>
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<td>11</td>
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<td>14</td>
<td>14</td>
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<tr>
<td>CES-D</td>
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<td>Mood</td>
<td>15</td>
<td>14</td>
<td>15</td>
<td>15</td>
<td>17</td>
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<tr>
<td>CES-D</td>
<td>13</td>
<td>Mood</td>
<td>16</td>
<td>16</td>
<td>16</td>
<td>17</td>
<td>15</td>
</tr>
<tr>
<td>EQ-5D</td>
<td>Pain</td>
<td>Energy/WB</td>
<td>17</td>
<td>17</td>
<td>17</td>
<td>16</td>
<td>16</td>
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<tr>
<td>CES-D</td>
<td>9</td>
<td>Mastery</td>
<td>18</td>
<td>18</td>
<td>18</td>
<td>18</td>
<td>18</td>
</tr>
<tr>
<td>CES-D</td>
<td>15</td>
<td>Support</td>
<td>19</td>
<td>19</td>
<td>20</td>
<td>19</td>
<td>19</td>
</tr>
<tr>
<td>CES-D</td>
<td>19</td>
<td>Support</td>
<td>20</td>
<td>20</td>
<td>19</td>
<td>20</td>
<td>20</td>
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<tr>
<td>EQ-5D</td>
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<td>Activity</td>
<td>21</td>
<td>21</td>
<td>22</td>
<td>21</td>
<td>21</td>
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<td>EQ-5D</td>
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<td>22</td>
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<td>EQ-5D</td>
<td>Self-care</td>
<td>Activity</td>
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<td>23</td>
<td>23</td>
<td>23</td>
</tr>
</tbody>
</table>

*All Kruskall Wallis tests of rank result in P>0.05

** All items in bold are those whose rank presents reasons to explore item anomalies
Table 4.5: Principal Component (PC) summary displaying the percent of the total variance accounted for by each principal component

<table>
<thead>
<tr>
<th>PC</th>
<th>Eigen</th>
<th>%</th>
<th>Cumm%</th>
<th>StdErr</th>
</tr>
</thead>
<tbody>
<tr>
<td>PC001</td>
<td>2.408</td>
<td>10.47</td>
<td>10.47</td>
<td>0.333</td>
</tr>
<tr>
<td>PC002</td>
<td>2.025</td>
<td>8.81</td>
<td>19.27</td>
<td>0.276</td>
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<td>PC003</td>
<td>1.680</td>
<td>7.30</td>
<td>26.58</td>
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<tr>
<td>PC004</td>
<td>1.292</td>
<td>5.62</td>
<td>32.19</td>
<td>0.175</td>
</tr>
<tr>
<td>PC005</td>
<td>1.216</td>
<td>5.29</td>
<td>37.48</td>
<td>0.164</td>
</tr>
<tr>
<td>PC006</td>
<td>1.103</td>
<td>4.80</td>
<td>42.28</td>
<td>0.146</td>
</tr>
<tr>
<td>PC007</td>
<td>1.064</td>
<td>4.63</td>
<td>46.90</td>
<td>0.145</td>
</tr>
<tr>
<td>PC008</td>
<td>1.051</td>
<td>4.57</td>
<td>51.47</td>
<td>0.142</td>
</tr>
<tr>
<td>PC009</td>
<td>1.037</td>
<td>4.51</td>
<td>55.99</td>
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</tr>
<tr>
<td>PC010</td>
<td>0.981</td>
<td>4.27</td>
<td>60.25</td>
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<tr>
<td>PC011</td>
<td>0.957</td>
<td>4.16</td>
<td>64.41</td>
<td>0.125</td>
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<tr>
<td>PC012</td>
<td>0.896</td>
<td>3.90</td>
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<tr>
<td>PC013</td>
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<td>71.97</td>
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<td>79.04</td>
<td>0.107</td>
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<td>82.42</td>
<td>0.101</td>
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<td>PC017</td>
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<td>3.32</td>
<td>85.74</td>
<td>0.103</td>
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<td>PC018</td>
<td>0.728</td>
<td>3.16</td>
<td>88.91</td>
<td>0.098</td>
</tr>
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<td>PC019</td>
<td>0.708</td>
<td>3.08</td>
<td>91.99</td>
<td>0.096</td>
</tr>
<tr>
<td>PC020</td>
<td>0.704</td>
<td>3.06</td>
<td>95.04</td>
<td>0.093</td>
</tr>
<tr>
<td>PC021</td>
<td>0.602</td>
<td>2.62</td>
<td>97.66</td>
<td>0.081</td>
</tr>
<tr>
<td>PC022</td>
<td>0.574</td>
<td>2.50</td>
<td>99.16</td>
<td>0.081</td>
</tr>
<tr>
<td>PC023</td>
<td>-0.037</td>
<td>-0.16</td>
<td>100.00</td>
<td>0.043</td>
</tr>
</tbody>
</table>

Cumm% = cumulative percent
StdErr = Standard Error
Figure 4.1: Person-item threshold distribution

Person-Item Threshold Distribution
(Grouping Set to Interval Length of 0.20 making 60 Groups)

No. Mean SD
Total [1201] -1.541 1.130
13.48

Location (logits)
**Figure 4.2** Items that were mapped to the conceptual model (n=23), with items ordered hierarchically based on difficulty.

<table>
<thead>
<tr>
<th><strong>Physical Energy and Well-being</strong></th>
<th><strong>Mood</strong></th>
<th><strong>Mastery</strong></th>
<th><strong>Engagement in meaningful activity</strong></th>
<th><strong>Support from others</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Restless sleep (CES-D 11)</td>
<td>Been a happy person (RAND 9h)</td>
<td>No way I can solve the problems I have (MS1)</td>
<td>Get going (RAND 9i)</td>
<td>People unfriendly (CES-D 15)</td>
</tr>
<tr>
<td>Full of Pep (RAND-9a)</td>
<td>Bothered by things that do not usually upset (CES-D 1)</td>
<td>Feel helpless in dealing with life’s problems (MS5)</td>
<td>Ability to perform usual activities (EQ-5d)</td>
<td>Support from family and friends has met my needs (cgQOL1)</td>
</tr>
<tr>
<td>Feel tired (RAND-9i)</td>
<td>Could not keep mind on things (CES-D 5)</td>
<td>Feel that I am being pushed around in life (MS2)</td>
<td></td>
<td>Felt like people disliked me (CES-D 19)</td>
</tr>
<tr>
<td>Proving care affecting health (cgQOL 33)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Worn out (CES-D)</td>
<td>Felt fearful (CES-D 10)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Global Health Perception</td>
<td>Crying Spells(CES-D 17)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain (EQ-5d)</td>
<td>Talked less than usual (CES-D 13)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mobility (EQ-5d)</td>
<td>Life a failure (CES-D 9)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*CES-D= the Center for Epidemiologic Studies Depression Scale; MS= Mastery scale; cgQOL=caregiver quality of life scale
CHAPTER 5

*Manuscript 4: Emotional Vitality in caregivers of stroke survivors: application of Rasch Measurement Theory to support a measure.*

Preface to *Manuscript 4*

At this point, qualitative and quantitative work in support of the theoretical basis of emotional vitality among caregivers of people with stroke has been reported (see Table 5.i for summary following this preface). Results suggest the inclusion of five core domains: (1) physical energy and well-being, (2) mood, (3) mastery, (4) engagement in meaningful activity, and (5) support from others; with a strong emphasis on the first two domains being most important for caregiver emotional vitality. In a second phase of concept development, this working model of emotional vitality was subjected to deductive quantitative testing using Rasch analysis of a secondary data set of 107 items answered by caregivers of stroke survivors (in this sense, akin to a factor analytical approach). The results suggested the five domains within emotional vitality construct could be mapped onto a unidimensional hierarchy covering the spectrum of measurement from low to high. The results indicated that a reduced subset definitely mapped, but that the vast majority of items had one or more anomalies that warranted further investigation.

As we are in the initial phase of understanding the concept of caregiver emotional vitality, it was felt that, in order for the construct to be captured in terms its theoretical development, a careful approach to measurement using Rasch Measurement Theory (RMT) was warranted. RMT has been described as an experimental psychometric paradigm used to examine the extent to which
observed rating scale data fit the assumption of an underlying hierarchical construct.91,95

The overall aim of this study was to contribute evidence towards the measurement properties of a set of items reflecting the emotional vitality latent construct as it pertains to caregivers of stroke survivors.
**Table 5.1 Concept development and evaluation**

<table>
<thead>
<tr>
<th>Steps</th>
<th>Purpose outlined by Morse</th>
<th>Purpose</th>
<th>Method(s)</th>
<th>Contribution to EV Theory Development</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Identification of the attributes</td>
<td>Identify abstract attributes indicative of the concept</td>
<td>To provide a framework for the conceptualization of emotional vitality as an important construct for rehabilitation professionals</td>
<td>1. Scoping Review</td>
<td>EV comprised of four domains:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2. ICF* Mapping Exercise</td>
<td>1. Energy</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2. Mood</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3. Mastery</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4. Engagement</td>
</tr>
<tr>
<td>2. Verification of the Attributes</td>
<td>To verify the conceptual attributes to search for indicators of those characteristics in other populations in which the concept appears or is used.</td>
<td>Identify domains associated with EV in caregivers and compare those with those identified in step one.</td>
<td>3. Qualitative interviews of caregivers of stroke survivors (n=30)</td>
<td>EV comprised of five domains:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1. Energy</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2. Mood</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3. Mastery</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4. Engagement</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5. Support from others</td>
</tr>
<tr>
<td>3. Quantitative testing</td>
<td>Subject model and set of dimensions, to deductive quantitative testing.</td>
<td>To contribute evidence that items fitting one or more aspects of emotional vitality map onto a unidimensional hierarchy and cover a continuum from low to high</td>
<td>4. Rasch analysis of 107 items related to the emotional of caregivers of stroke survivors (n=407)</td>
<td>23 items fit together uniformly to reflect a unidimensional concept covering the full range of emotional vitality of caregivers of stroke survivors. BUT construct validity poor.</td>
</tr>
<tr>
<td>4. Instrument development and testing</td>
<td>To develop a measure of a given concept given the conceptualization of the phenomena in question.</td>
<td>To contribute evidence towards the measurement properties of a set of items reflecting the emotional vitality latent construct as it pertains to caregivers of stroke survivors</td>
<td>5. Traditional psychometric testing Rasch Measurement Theory</td>
<td>Current Study</td>
</tr>
<tr>
<td></td>
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<td></td>
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<td>---</td>
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<td>---</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>Testing (future)</td>
<td>Validate in other populations or suggest a need for refinement of the original conceptualization</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>To contribute evidence towards the utility of the EVM as a useful, scientifically robust and clinically meaningful tool in other populations.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>Traditional psychometric testing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>Rasch Measurement Theory</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

ICF=International Classification of Functioning; EV=Emotional Vitality; EVM=Emotional Vitality Measure
Title Page

Title: Emotional Vitality in caregivers of stroke survivors: application of Rasch Measurement Theory to support a measure.

For submission to: Quality of Life Research

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Keywords: Rasch Measurement Theory, Emotions, caregiver
ABSTRACT

BACKGROUND: Emotional vitality is an emerging concept that describes an individual’s overall sense of physical energy and well-being, positive mood, personal mastery, and the ability to participate in meaningful activity. An important limitation to enhancing emotional vitality has been our inability to reliably quantify this construct with an interval level-measure.

OBJECTIVE: To contribute evidence towards the measurement properties of a set of items reflecting the emotional vitality latent construct as it pertains to caregivers of stroke survivors.

METHODS: Data for this study were drawn from a multi-site study of an inception cohort of caregivers of persons with stroke (n=409) who were followed over one year. Item generation involved screening all items in the data set (n=198) and mapping a list of potential clinically meaningful items to each domain a conceptual framework developed from previous studies. The items that emerged from these steps were selected for further evaluation using Rasch Measurement Theory.

RESULTS: Analyses conducted based on RMT supported a prototype emotional vitality measure (P-EVM) consisting of 19 items to quantify the latent trait. The overall fit of the model was good and stable across time. The measure was well targeted, with items and people covering the emotional vitality continuum. The mean fit for the caregivers was less than zero, indicating that emotional vitality of this sample was lower than expected from the items included.
CONCLUSION: The items from the P-EVM can be used to obtain interval level scores for emotional vitality for use in future research and clinical settings. Future work is needed to establish the interval nature and validity of this measure in other caregiving populations.
INTRODUCTION

Family caregivers constitute the largest group of care providers in North America, providing the majority of long-term care services to individuals with chronic health conditions.\(^{24,31,32}\) The estimated market value of caregiver activity for this population exceeds that spent on formal health care and nursing home care.\(^{17,26,34}\) This is especially true for care provided to stroke survivors. Despite losing the ability to live independently, the majority of stroke survivors (80%) are able to return to their homes because they receive assistance from family.\(^{27,170}\) Without caregiver assistance, the public costs of long-term care would increase dramatically, as many stroke survivors would require nursing home care to meet their basic needs.\(^{17,26,38}\) Although returning home is the highly desirable for most, supporting family members, often an aging spouse with their own age-related challenges, can become overwhelmed rapidly by responsibilities. Therefore, it is not surprising that caregiving is associated with adverse health and personal outcomes such as increased fatigue, mood disorders, isolation, functional decline and mortality.\(^{9,11,12,14,15,25-29}\)

Emotional vitality is an emerging concept that describes an individual’s overall sense of physical energy and well-being, positive mood, personal mastery, and the ability to participate in meaningful activity.\(^{20-22,51,52,145}\) While emotional vitality may serve as a critical buffer against the strain of caregiving, little is known about what enables some caregivers to thrive and be emotionally vital in the caregiving role. Understanding ways to preserve emotional vitality may help ensure
caregivers can continue to meet the physical and emotional needs of care recipients without a cost to their own health, quality of life, and emotional well-being.

An important limitation to enhancing emotional vitality in caregivers has been our inability to reliably quantify this construct. Emotional vitality, which is not directly observable, is traditionally inferred by analyzing responses thought to reflect key domains of an underlying personality trait. Latent constructs, such as emotional vitality, are often captured by summing the responses to questions that are scored on an ordinal rating scale. This approach has many limitations,\textsuperscript{86,164} not the least of which are the assumptions that the numerals assigned to the rating scale are additive and each item contributes equally to the total score.\textsuperscript{81,82} Only items measured on an interval scale, where the units are equally spaced, should be added to produce a total score.\textsuperscript{65}

Modern psychometric approaches exist to address these limitations and to support the creation of measures from a collection of items by producing a mathematically valid total score that is both clinically meaningful and interpretable. These methods are guided by two schools of thought: (1) Item Response Theory (IRT)\textsuperscript{89,90} and (2) Rasch Measurement Theory (RMT).\textsuperscript{91,92} IRT is a statistical modeling paradigm that is used to find mathematical models that explain data.\textsuperscript{94} In comparison, RMT has been described as an experimental psychometric paradigm used to examine the extent to which observed rating scale data fit the assumption of an underlying hierarchical construct.\textsuperscript{91,95} Items and people that do not fit this underlying model would then be the focus of further study to understand their unexpected behavior.
The Rasch model, named for the Danish mathematician Georg Rasch (1901-1980), is widely used in health outcome measurement to transform ordinal response categories onto a linear scale with interval-like properties. It is based on a logit transformation of the probability of response to a particular item; an item that 50% of respondents pass or endorse has a logit of 0. A scale that defines the full spectrum of a construct will range from -4 to +4 logits, corresponding to ±4 standard deviations defining the full range of a standard normal distribution. People at the low end of the logit scale have less ability whereas people at the high end have more ability; correspondingly, items at the low end are easy to pass or endorse, items at the high end are difficult to pass or endorse. A range of parameters arising from the Rasch analysis can be used to judge misfit and as a result, the extent to which scoring and summing is defensible in the data collected according to the Rasch model. The development of items and testing of measurement scales using both IRT and RMT requires a strong theoretical basis upon which to evaluate the mathematical properties of the items and the total score. Previous qualitative and quantitative work by our group has been reported on support of the theoretical basis of emotional vitality among caregivers of people with stroke. Results suggested the inclusion of five core domains: (1) physical energy and well-being, (2) mood, (3) mastery, (4) engagement in meaningful activity, and (5) support from others; with a strong emphasis on the first two domains being most important for caregiver emotional vitality. In a second phase of concept development, this working model of emotional vitality was subjected to deductive quantitative testing using Rasch analysis of a secondary data set of 107 items answered by
caregivers of stroke survivors (in this sense, akin to a factor analytical approach). The results suggested the five domains within emotional vitality construct could be mapped onto a unidimensional hierarchy covering the spectrum of measurement from low to high. The results indicated that a reduced subset definitely mapped, but that the vast majority of items had one or more anomalies that warranted further investigation. As we are in the initial phase of understanding the concept of caregiver emotional vitality, it was felt that, in order for the construct to be captured in terms its theoretical development, a careful approach to measurement using RMT was warranted. Thus, the overall aim of this study was to contribute evidence towards the measurement properties of a set of items reflecting the emotional vitality latent construct as it pertains to caregivers of stroke survivors.

**METHODS**

*Source of Data*

Data for this study were drawn from a multi-site study of an inception cohort of individuals (n=678) with stroke who were followed over time for the purposes of understanding changes and contributors to health-related quality of life. Family members who would be providing the post-discharge care for members of this cohort were also recruited along with the person with stroke. The methods for this study have been previously described. Caregivers answered 198 items drawn from validated scales assessing health-related quality of life, disability, physical and emotional well-being at 1, 3, 6 and 12 months post stroke. Items came from
the RAND-36, Positive and Negative Affect Scale, Center for Epidemiological Depression Scale, EQ-5D, Mastery Scale, Caregiver Impact Scale, and the Caregiver Quality of Life Scale. The original study was approved by the McGill University Institutional Review Board.

**Item Generation and Reduction**

Item generation involved screening all items in the data set (n=198) and mapping a list of potential clinically meaningful items to each domain of our conceptual framework. Next, each item was inspected for inclusion based on four guiding principles outlined by Hibbard: (1) contribution of substantive content central to the construct being measured; (2) adequate coverage across the measurement continuum from easy to difficult; (3) precise location on the measurement scale (e.g. small standard error of measurement); and (4) contribution of unique information about the amount of the construct (not redundant) to justify the response burden created by inclusion of the item. The items that emerged from these steps were selected for further evaluation.

**Applying RMT**

As items were on ordinal scales, each had \( k \) ordinal response options yielding \( k-1 \) thresholds (the number of progressions from lower to higher). Masters’ partial credit model was used to guide a series of iterative steps that examined the overall, item, and person fit statistics to the Rasch model. All analyses were performed using Rasch Unidimensional Measurement Model (RUMM2030) software.
**Item Hierarchy Hypothesis.** A preliminary ordering of item difficulty was hypothesized *a priori* (see Appendix A) and was tested against the final hierarchy using the Wilcoxon rank-sum test.

**Response option structure.** The aim of the analysis was to have a bank of items which are ordered hierarchically from least difficult to most difficult.\(^{175}\) This hierarchy is represented by the Guttman\(^ {176}\) response pattern which shows a progression of item thresholds ranked according to person ability. A true Guttman response pattern would show non-endorsement of easy items for people with low ability with a gradual progression of endorsement of harder items as person ability increases. The Guttman response pattern is, therefore, the most probable response pattern for a person when items and thresholds are ordered. In RUMM 2030, the Guttman response pattern is presented as a visual display which can be inspected for adherence to the optimal structure (both items and thresholds). This visual inspection can reveal items and/or people behaving aberrantly.

**Threshold ordering.** Threshold probability curves, category probability curves, and threshold locations were visually inspected to identify items not behaving as expected given the person’s ability on the latent trait. For example, respondents who endorsed items about having energy on *some days* were more likely to have higher levels of emotional vitality than those who endorse this item *none of the time*.

**Item fit statistics.** Overall item fit was examined via the mean item fit residual which is based on the standardized residuals of the responses of all persons to the
item. If the data fit the model, the value is expected to have a mean of 0 and a standard deviation of 1. Misfit would imply that the items are not working as intended along the latent trait defined by the item pool and suggest that the items may not be measuring the intended construct.78

Individual item misfit was examined using four methods: (1) inspection of the individual item fit residuals (-2.5 to +2.5), (2) chi-square ($\chi^2$) test results, (3) F-test results, and (4) visual inspection of the item characteristics curves (ICCs). For $\chi^2$ test and F-test, a statistically significant result ($p<0.05$) indicated poor fit of the item. To account for multiple testing, Bonferroni corrections were made to the significance levels of the $\chi^2$ and F-tests based on the number of items in the scale. Item characteristics curves were visually inspected to compare the proportions of individuals in class intervals with the expected theoretical probabilities predicted under the Rasch Model. Visually, good fit is observed when the class intervals fall along the theoretical curve. The ICCs of all items collectively were also inspected for the optimal “parallel pattern”, a distinctive property of the Rasch model which shows that no matter where along the latent trait a person is located, the distance between less and more difficult items is the same. The corollary is that no matter which items are administered, a person with more ability will have a higher probability of responding to the more difficult items than a person with less ability. These are requirements for measurement invariance.91,155

*Item Locations.* The locations of the items on the continuum were compared to identify redundancy (i.e., several items at the same location).
Overall person fit. Overall person fit of the caregivers was examined using the mean person fit residual. Similar to the item fit residual, the overall fit of persons to the model is expected to have a mean value of 0 and a standard deviation (SD) of 1.

Individual person misfit. Examination of individual person misfit was assessed via the individual person fit residuals such that a residual greater than 2.5 was considered indicative of a person having an unexpected response pattern (under the Rasch model) warranting further investigation of the individual and to explore reasons for the anomalous behavior.\textsuperscript{177}

Overall fit to the Rasch model. The item-trait interaction $\chi^2$ statistic is calculated for persons within each class, as the sum of the discrepancies between the observed scores and their expected values according to the model. The desired outcome is this $\chi^2$ value calculated from the items does not depend on class interval (interaction between item and class). A statistically significant result of the $\chi^2$ test indicates that the hierarchical ordering of the items was not constant along the latent trait and an interval score has not yet been created.

Person Separation Index (PSI). Reliability was assessed by using the person separation index (PSI)\textsuperscript{178}, which is analogous to the Cronbach’s alpha.\textsuperscript{154} The PSI was used to quantify the reliability of the values on latent trait along the continuum with higher values indicating greater reliability.\textsuperscript{78,163} A value of 0.70 and above was considered acceptable as an indicator for group use, and 0.70-0.85 for individual use.\textsuperscript{178}
Local Dependency and Unidimensionality. Item-item correlations were examined and local dependency was ruled out if correlations were < 0.3.\textsuperscript{179} Multidimensionality was also assessed by examining how items loaded onto the first principal component of residual scores.\textsuperscript{180} In the event that two sub-groups of items are formed, (one comprising all the highest positive loading items and another for all the lowest negative loading items), Smith independent t-tests\textsuperscript{180} were used to compare average person locations for extremes groups of items. The percentage of tests outside the range ±1.96 SD is computed and if less than 5% of the tests are significantly different, assumptions for unidimensionality are met.\textsuperscript{92,180}

Differential Item Functioning (DIF) refers to the extent to which each item’s location is stable across subgroups. In this study DIF was examined for time since stroke (1, 3, 6, 12 months post-stroke), age (<50, 51-65, 66-75, 76 years or over), gender (men/women), and acknowledgement of children (yes/no) using a Bonferroni corrected two-way analysis of variance (ANOVA) (factor 1 as location on the latent trait and factor 2 is variable under consideration for DIF).

Targeting of the scale is reflected by a close correspondence between the mean person and item locations, when the latter is constrained to be zero. Optimal targeting would have a mean person location of 0; values <0 suggest that the average item difficulty is above the average emotional vitality of the sample. Items that met the criteria for Rasch measurement, collectively referred to as the Prototype - Emotional Vitality Measure (P-EVM), were further assessed for data completeness (percent missing from each item), scaling assumptions (similarity of
item means and variances; magnitude and similarity of corrected item-total correlations, scale to sample targeting); and floor and ceiling effects using SAS version 9.2 (SAS Institute Inc. 2009. SAS® 9.2 Macro Language: Cary, NC: SAS Institute Inc.).

RESULTS

The pooled sample over four points in time (n=1183) comprised of 284 women (69.4%) and 125 men (30.6%). The mean age was 58.4 years (SD: 14.1) and 84.3% of caregivers reported living with the stroke survivor during the study period. Most had at least one child (80.8%) and 245 participants (59.9%) had achieved some college education. The mean caregiver onset was 36 days post stroke (SD=21, range 0–78 days). Items were available for 341 caregivers at time 1 and 307, 272, and 263 for subsequent time points.

Item Generation and Preliminary Scale Formation

From the pool of items in the data set, 107 items mapped back to the five core domains. After applying Hibbard’s guidelines for item selection, 22 items were retained to form the prototype measure of emotional vitality (P-EVM).

Response options. The item response options for 13/22 (59%) items were disordered, indicating that the categories were not working as intended in the prototype measure. Disordered items were rescored, as shown in Figure 5.1 (part B).
After rescoring, there was statistical and graphical evidence for misfit of 3 items. Two were removed based on strong statistical evidence that the items did not fit this Rasch model. These items were: “Caregiving interfered with active recreation” (Caregiver Impact Scale item 5: fit residual=-3.64; $\chi^2=42.67$, df=9, p<0.01) and “I have financial concerns because of the impact of the stroke/caregiving” (Caregiver Quality of Life Scale item 11: fit residual=3.10; $\chi^2=23.26$, df=9, p<0.01). Both items also had ICCs well below the theoretical curve, providing evidence of poor discrimination ability. Figure 2 shows that the item, “There is little I can do to change most of the important things in my life” (Mastery item 7) was consistent with guessing such that caregivers of lower ability were as or more likely to endorse this item compare to those of higher ability. This item was removed.

Item Fit. Item locations and their standard errors are reported in Table 5.1. Fit of the items was adequate, with all items meeting the requirements. Figure 5.1 (part C) illustrates the item threshold range, with values spanning -3.70 to +2.72 items covered 80% of the linear continuum along which caregivers could be measured. The ordering of the item reflected our original hypothesis.

Overall item fit was good with a mean (SD) of -0.69 (1.06) as shown in Table 5.1. Item residuals, $\chi^2$ fit statistic, or the F-test after Bonferroni correction also did not show evidence of misfit.

Person Fit. Figure 1a shows the distribution of person measurements along the measurement continuum, ranging from -4.30 to +2.86, reflecting a broad, but
uneven spread. Overall person fit as described by the mean person fit residual was below the targeted level of 0 (mean location= -1.31, SD=1.10).

Person locations ranged from -5.30 to +3.57, with 15 individuals lying outside of the individual fit residual range of -2.5 to +2.5. In a sensitivity analysis, removal of these people improved the overall fit of the P-EVM to the Rasch model.

Common attributes of the individuals removed was that they only completed 3 items of a possible 19.

Scale-to-sample targeting. Figures 1a and 1c show the targeting of the caregiver sample to the 19 items remaining items. The scale-to-sample targeting plots indicate that this was a reasonable sample for evaluating the P-EVM’s performance as a measure. However, of note is that the person location is negative; providing evidence that the average item difficulty is higher than the average person ability.

Overall model fit. Adequate fit of the data to the Rasch model was observed with an overall non-statistically significant result on the item-trait chi-square test ($\chi^2$= 202.26, DF=117, p=0.06). Summary statistics are reported in Table 5.2.

Person Separation Index. Scale reliability was high with a PSI of 0.85, indicating the items adequately separated this sample of caregivers along the latent trait.

Local Dependency and Unidimensionality and Local Dependency. There was one positive residual correlation larger than 0.3 between item RAND-36 9e “I have a lot of energy” and RAND 9i, “I feel tired” ($r$=0.388). There was little evidence of
response dependency between other items with correlations ranging from -0.341 to 0.204.

Examination of the Eigenvalues from the principal component analysis suggested that the presence of two or more subscales. This was also supported by the loadings in the first principal component that showed clear patterns of residuals on successive components, with 3 items with large positive correlations, and 6 others with negative loadings. Of note, the 3 positive items queried energy. Evidence from the t-test grouping these items together in subtests revealed that the amount of multi-dimensionality was of borderline relevance, with 10.1% of the subtests (n=120) showing significant differences in the estimated differences generated (t=-3.21, p=0.03). This was a significant deviation from the 5% expected value and warrants further consideration.

Differential Item Functioning. Both graphical and statistical evidence showed the difficulty level of the items was uniform across education, language, income, and presence of children. However, men did not respond as consistently as women on the items “I feel tired” and “I have a lot of energy” meeting statistical but not graphical evidence for DIF by gender.

Item hierarchy. The Wilcoxon Rank Sum test indicated no significant deviation from the a priori ranking of the items (p=0.34). Visual inspection of the item ordering showed that two items, “Able to participate in passive recreation” and “Life a failure,” were more difficult than expected at all time points (each deviating from the expected rank by one).
Data completeness. Missing data from the majority of the items ranged from <1%-13% except for an item from the Mastery Scale (item 5) (18.3%). Scale scores were computable for 97.5% of respondents. As this was a secondary analysis of an existing data set, respondents who filled out ≤ 3 items were excluded (n=15) as the data they provided could not adequately represent the construct under investigation.

Targeting. Criteria for adequate scale-to-sample targeting were satisfied. Scores spanned the range of the scale and were not notably skewed. There was little evidence of ceiling and floor effects.

DISCUSSION

The aim of this study was to contribute evidence towards the measurement properties of a set of items reflecting emotional vitality as it pertains to caregivers of persons who have experienced a stroke. Analyses conducted based on RMT supported a prototype measure consisting of 19 items to quantify the latent trait. The overall fit of the model was good and stable across time. The measure was well targeted, with items and people covering the emotional vitality continuum. The mean fit for the caregivers was less than zero, indicating that emotional vitality of this sample was lower than expected from the items included. Considering this was a group of individuals who had experienced a significant life event requiring re-adaptation, the deviation was not surprising and reflective of what is known thus far about the emotional burden of caregivers post-stroke. In the first year, caregivers often report high levels of depressive
symptoms and anxiety, poor physical health, difficult learning new tasks, and having little time for family and friends.\textsuperscript{27,173,183,184}

A finding of particular note is that the item location did not vary across time. This must not be confused with change over time on the construct which will be the subject of future analyses. Differential item functioning across time can indicate the presence of recalibration response shift,\textsuperscript{185} which would indicate an anomaly in the data which might need to be remedied by a change in the response options. For example, items that are worded in terms of difficult are sensitive to response shift as a person’s concept of what is difficult or challenging may change over time.\textsuperscript{186}

Previous research on quantifying the “impact” of informal caregiving has identified a total of 105 indices used to capture caregiver burden,\textsuperscript{187} three of which are specific to caregivers of stroke patients. These scales measure varying dimensions of the caregiving experience, primarily burden and distress reflected in energy and mood items.\textsuperscript{19,21-23} Some assess emotional vitality with a single index such as the General Well-Being Schedule\textsuperscript{60} (GWBS) or by combining items from several subscales such as the Center for Epidemiological Studies-Depression Scale (CES-D)\textsuperscript{80} and the Geriatric Depression Scale (GDS),\textsuperscript{61} inferring that emotional vitality is largely the inverse of depressive symptoms. Emotionally vitality has also been used interchangeably with the term vitality. This term is pervasive in the literature, perhaps reflective of two commonly used measures, the SF-36\textsuperscript{68} and the Profile of Mood States (POMS),\textsuperscript{132} which label one of their
constructs as “vitality.” In both of these measures, this term is intended to reflect the continuum of energy, and fatigue. However, our previous conceptual work suggest that emotional vitality reflects more than simply energy/fatigue and should be assessed with items that capture all relevant domains. If indeed emotional vitality is modifiable and can contribute to achieving positive health outcomes, reliable and valid measurement of the theoretical construct, as described by stroke caregivers, is essential to further advancement. The P-EVM is a starting point to understand this construct further and identify those caregivers who may be languishing in their roles.

A particular strength of this study was the application of Rasch measurement methods for scale development and item reduction using a strong conceptual model. We were able to utilize existing data drawn from ordinal scales and develop an interval-like measure. The result is a scale with mathematical properties of linearity, additivity, and separability. As theorized, items from the physical energy domain fell at the lower end of hierarchy, such that if someone said they slept well (1 point), but did not endorse any other item, they would score 1/44 on the measure. To gain a further point, they would endorse “feeling full of pep” only some of the time but not endorse any other items (2/44). In order to get the top score (44/44) people would have to have the highest level of all previous items and endorse that their needs were being adequately met by friends and family. Having support needs met was a priori identified as indicating the highest level of emotional vitality. The ordering of the items suggest that in the first year, caregivers who develop strategies to manage their energy, reconstitute their family life, maintain family routines, and develop a
safety net of family/healthcare/financial support feel better equipped to provide the level of support needed for the person with stroke.\textsuperscript{181} It is hypothesized that with the onset of new responsibilities, physical energy and well-being may likely be first impacted, followed by loss of ability to participate in meaningful activity, the ability to maintain healthy relationships, and regulate both negative and positive mood. This hypothesis would need to be tested further both qualitatively and quantitatively across different caregiver samples.

Another advantage of using RMT to guide our analyses was it provided a hypothetical unidimensional line along which items and persons are located according to their difficulty and ability measures. Items that fall close to the hypothetical line contribute to the measurement of a single dimension defined by the theoretical model. Gaps along the hypothetical line indicate that there are large distances between item difficulties so people who fall in ability close to this part of the line are not as precisely measured by means of the test.\textsuperscript{188} In our study, there was some evidence to suggest that the measure had more than one dimension. This could have arisen by chance or because of true multidimensionality. Three items representing energy (pep, energy, tired) from the RAND-36 could have formed an energy subscale if desired. However, the premise underlying the concept of emotional vitality is that, in the presence of a serious and complex health threat, a cascade of sequelae can blur the boundaries between single effects or impairments such as fatigue, anxiety, depression, loss of confidence, and feeling unsupported. Because we were using items from legacy measures, the wording may not have been optimal for reflecting a more global
construct of emotional vitality. In addition, it is possible that the fixed order of administration may also have influenced the responses.

Regarding gaps along the hypothetical line resulting with 19 items, gaps were observed in two places along the continuum from -2.7 to -1.9 & 2.5 to 4.0 (see Figure 1C). The first gap on the negative end of the continuum was filled when all 22 items were included. Once three items were removed due to strong statistical and graphical evidence, the remaining 19 items captured all but one of the theoretical domains. The ‘mastery’ domain had only one item in our prototype measure. In the earlier qualitative work performed by our group, caregivers stressed the importance of feeling able to successfully accomplish new tasks, both related to caregiving and taking on the roles that the care recipient as well (e.g., financial management, home maintenance, grocery shopping). The items currently in this version of the P-EVM do not reflect this important aspect of caregiver emotional vitality and perhaps reflect the gaps along the hypothetical line. This would guide further development of this measure.

**Strengths and Limitations**

A key strength of this study is the use of an inception cohort of people with stroke to identify caregivers which reduces bias and strengthens generalizability to other stroke cohorts. In addition, the analysis of existing data is an efficient and ethical way to maximize the knowledge garnered from previous work and can be used to justify the collection of new data to strengthen the knowledge base. However, analysis of the secondary data may restrict generalizability. Although this archived data provided rich material to be re-analyzed, the data was collected for a
specific purpose (understand HQOL of people with stroke and their caregivers) and not specifically to generate items for an eventual measure of emotional vitality.\textsuperscript{150} It would therefore be important to conduct further testing of the prototype measure on additional samples of caregivers and in other caring situations. While this study only had access to data on caregivers starting at one-month post stroke, this is the time period when the majority of patients are exiting the hospital.

CONCLUSION

In this study, we used an approach guided by modern methods to develop a 19 item prototype for a measure of emotional vitality for stroke caregivers. Our results provide evidence for the content, structure, validity, and reliability of the P-EVM to assess the level of emotional vitality of caregivers post-stroke. Future work with caregivers is needed to further strengthen the content validity of the P-EVM and to identify new items, particularly for the mastery domain. Emotional vitality embodies core domains that individuals can draw upon to combat sudden stressors such as health events, physical decline, or life changing experiences such as stroke. Capturing this resource quantitatively will enable healthcare professionals to learn more about caregiver needs and develop plans of support to ensure the health and emotional vitality for both caregivers and care recipients is optimized.
Table 5.1 Characteristics of the items mapped to the concept of emotional vitality using Rasch Analysis (Items are listed in order of difficulty from hardest to easiest)

<table>
<thead>
<tr>
<th>#</th>
<th>Index</th>
<th>Item</th>
<th>Domain</th>
<th>Description</th>
<th>Difficulty</th>
<th>SE</th>
<th>Fit residual</th>
<th>$\chi^2$†</th>
<th>F-Statistic†</th>
</tr>
</thead>
<tbody>
<tr>
<td>19</td>
<td>CG-QOL</td>
<td>36</td>
<td>Support</td>
<td>Friends and family met needs</td>
<td>2.401</td>
<td>0.157</td>
<td>-0.071</td>
<td>4.318</td>
<td>0.671</td>
</tr>
<tr>
<td>18</td>
<td>CES-D</td>
<td>15</td>
<td>Mood</td>
<td>People unfriendly</td>
<td>1.619</td>
<td>0.116</td>
<td>-1.341</td>
<td>5.250</td>
<td>0.734</td>
</tr>
<tr>
<td>17</td>
<td>CES-D</td>
<td>9</td>
<td>Mood</td>
<td>Life a failure</td>
<td>1.215</td>
<td>0.101</td>
<td>-0.206</td>
<td>16.427</td>
<td>2.466</td>
</tr>
<tr>
<td>16</td>
<td>CIS</td>
<td>10</td>
<td>Support</td>
<td>Family relations*</td>
<td>0.577</td>
<td>0.064</td>
<td>-1.623</td>
<td>11.093</td>
<td>1.568</td>
</tr>
<tr>
<td>15</td>
<td>CIS</td>
<td>8</td>
<td>Support</td>
<td>Relationship with spouse</td>
<td>0.383</td>
<td>0.061</td>
<td>-0.251</td>
<td>8.375</td>
<td>1.075</td>
</tr>
<tr>
<td>14</td>
<td>CES-D</td>
<td>3</td>
<td>Mood</td>
<td>Talk less than usual</td>
<td>0.357</td>
<td>0.079</td>
<td>-0.774</td>
<td>4.908</td>
<td>0.563</td>
</tr>
<tr>
<td>13</td>
<td>CG-QOL</td>
<td>5</td>
<td>Support</td>
<td>Relationships with friends</td>
<td>0.290</td>
<td>0.055</td>
<td>-1.663</td>
<td>16.478</td>
<td>2.443</td>
</tr>
<tr>
<td>12</td>
<td>CG-QOL</td>
<td>4</td>
<td>Mastery</td>
<td>Ability to perform daily activity</td>
<td>0.088</td>
<td>0.053</td>
<td>0.932</td>
<td>12.892</td>
<td>1.628</td>
</tr>
<tr>
<td>11</td>
<td>CES-D</td>
<td>10</td>
<td>Mood</td>
<td>Felt fearful</td>
<td>-0.074</td>
<td>0.073</td>
<td>-1.175</td>
<td>8.878</td>
<td>1.071</td>
</tr>
<tr>
<td>10</td>
<td>CG-QOL</td>
<td>29</td>
<td>Mastery</td>
<td>Felt depressed</td>
<td>-0.089</td>
<td>0.036</td>
<td>-0.969</td>
<td>11.650</td>
<td>1.358</td>
</tr>
<tr>
<td>9</td>
<td>CIS</td>
<td>3</td>
<td>Engagement</td>
<td>Employment*</td>
<td>-0.130</td>
<td>0.078</td>
<td>-0.459</td>
<td>7.264</td>
<td>0.944</td>
</tr>
<tr>
<td>8</td>
<td>CES-D</td>
<td>18</td>
<td>Mood</td>
<td>Felt sad</td>
<td>-0.140</td>
<td>0.041</td>
<td>-1.977</td>
<td>20.983</td>
<td>2.472</td>
</tr>
<tr>
<td>7</td>
<td>CIS</td>
<td>6</td>
<td>Engagement</td>
<td>Passive recreation*</td>
<td>-0.316</td>
<td>0.051</td>
<td>1.805</td>
<td>18.020</td>
<td>2.159</td>
</tr>
<tr>
<td>6</td>
<td>Mastery</td>
<td>5</td>
<td>Mastery</td>
<td>Future mostly depends on me</td>
<td>-0.364</td>
<td>0.052</td>
<td>1.234</td>
<td>13.443</td>
<td>1.505</td>
</tr>
<tr>
<td>5</td>
<td>CIS</td>
<td>4</td>
<td>Engagement</td>
<td>Household responsibilities*</td>
<td>-0.484</td>
<td>0.050</td>
<td>-0.492</td>
<td>10.895</td>
<td>1.111</td>
</tr>
<tr>
<td>4</td>
<td>RAND-36</td>
<td>9i</td>
<td>Energy</td>
<td>Feel tired</td>
<td>-1.128</td>
<td>0.030</td>
<td>-1.458</td>
<td>4.817</td>
<td>0.649</td>
</tr>
<tr>
<td>3</td>
<td>RAND-36</td>
<td>9e</td>
<td>Energy</td>
<td>Have a lot of energy</td>
<td>-1.194</td>
<td>0.029</td>
<td>0.767</td>
<td>22.278</td>
<td>2.462</td>
</tr>
<tr>
<td>2</td>
<td>RAND-36</td>
<td>9a</td>
<td>Energy</td>
<td>Full of pep</td>
<td>-1.440</td>
<td>0.028</td>
<td>-2.411</td>
<td>12.365</td>
<td>1.586</td>
</tr>
<tr>
<td>1</td>
<td>CES-D</td>
<td>11</td>
<td>Energy</td>
<td>Sleep was restless</td>
<td>-1.571</td>
<td>0.065</td>
<td>0.655</td>
<td>10.110</td>
<td>0.912</td>
</tr>
</tbody>
</table>

†=Degrees of Freedom=9; *=interference with

- CES-D= Center for Epidemiologic Studies-Depression Scale; CG-QOL= Caregiver Quality of Life Scale; CIS=Caregiver Impact Scale; RAND-36= RAND Quality of Life Index
Table 5.2: Summary of Global Fit Statistics for the Rasch Model

<table>
<thead>
<tr>
<th>ITEM-TRAIT INTERACTION</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Item Chi-Square</td>
<td>202.26</td>
</tr>
<tr>
<td>Total Deg of Freedom</td>
<td>171</td>
</tr>
<tr>
<td>Total Chi-Square Probability</td>
<td>0.06</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ITEM-PERSON INTERACTION ITEM</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty</td>
<td>0.00±1.00</td>
</tr>
<tr>
<td>Fit Residual</td>
<td>-0.69±1.01</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PERSON</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Measure</td>
<td>-1.32±1.08</td>
</tr>
<tr>
<td>Fit Residual</td>
<td>-0.33±0.90</td>
</tr>
</tbody>
</table>
**Appendix 5A:** A-priori hypothesis about item hierarchy within each domain according to the conceptual model (n=22 items).

### EMOTIONAL VITALITY

<table>
<thead>
<tr>
<th>Physical Energy and Well-being</th>
<th>Mood</th>
<th>Mastery</th>
<th>Engagement in meaningful activity</th>
<th>Support from others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Restless sleep (CES-D 11)</td>
<td>Felt sad (CES-D 18)</td>
<td>What happens in the future depends on my (MS6)</td>
<td>Able to participate in meaningful passive recreation (CIS 6)</td>
<td>Able to maintain relationships with friends (cgQOL5)</td>
</tr>
<tr>
<td>Full of Pep (RAND9a)</td>
<td>Felt depressed (cgQOL 29)</td>
<td>Providing care limits my ability to perform regular daily activities well (cgQOL 4)</td>
<td>Caregiving interferes with household responsibilities (CIS 4)</td>
<td>Caregiving interferes with relationship with your spouse (CIS 8)</td>
</tr>
<tr>
<td>Have a lot of energy (RAND 9e)</td>
<td>Felt fearful (CES-D 10)</td>
<td>Feel helpless in dealing with life’s problems (MS5)</td>
<td>Able to participate in meaningful active recreation (CIS 5)</td>
<td>Caregiving interferes with your family relations (CIS 10)</td>
</tr>
<tr>
<td>Feel tired (RAND 9i)</td>
<td>Talked less than usual (CES-D 13)</td>
<td></td>
<td>Caregiving interferes with employment (CIS 3)</td>
<td>Friends and family have met my needs (cgQOL 36)</td>
</tr>
<tr>
<td>People unfriendly (CES-D 15)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life a failure (CES-D 9)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* CES-D= the Center for Epidemiologic Studies Depression Scale; MS= Mastery scale; cgQOL=caregiver quality of life scale
Figure 5.1A: Distribution of emotional vitality items of people of caregivers in the sample, obtained by converting total raw scores into linear measurements. Figure 5.1B: Item map showing a person’s expected score to each item as a function of the measure of emotional vitality. The items are listed in terms of difficulty. Figure 5.1C: The location of the 22 items, relative to each other, on an interval scale.
Figure 5.2: Item removed from Model. Example of guessing
CHAPTER 6: Manuscript 5 Trajectories of emotional vitality of caregivers of stroke survivors in the first year of caregiving.

Preface to Manuscript 5

At this stage, if this was not a doctoral thesis, I would administer the P-EVM on a different sample of stroke caregivers to test the items. In the context of a doctoral thesis, the availability of the longitudinal data afforded the opportunity to “pre-test” longitudinal validity by amassing preliminary evidence for how this measure might behave over time. While not conclusive, this demonstration shows how future modeling of longitudinal change might be optimized.

Thus, the overall aim of this study was to contribute to a preliminary understanding of the stroke caregiving experience by taking a longitudinal view of emotional vitality. The specific objectives were to estimate the extent to which (i) caregiver emotional vitality changes in the first caregiving year; and (ii) caregiver characteristics and the functional profile of the care recipient impacts a caregiver’s emotional vitality in the first year.
Title Page

Title: Trajectories of emotional vitality of caregivers of stroke survivors in the first year of caregiving.

For submission to: Rehabilitation Psychology

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Keywords: Emotion, Caregiver, Trajectory

RUNNING HEAD: Caregiver Emotional Vitality

Conflicts of Interest: No conflicts of interest have been declared by the authors

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ABSTRACT

Introduction: Emotional vitality is an emerging concept that describes an individual’s overall sense of emotional well-being after a catalytic health or life event. In the context of caring for someone with a stroke, caregiver emotional vitality may be an important modifiable target for intervention by rehabilitation professionals to improve health outcomes of both caregivers themselves and the individuals who experienced a stroke.

Objectives: The overall aim of this study was to contribute to the understanding of the stroke caregiving experience by taking a longitudinal view of emotional vitality. The specific objectives were to estimate the extent to which (i) caregiver emotional vitality changes in the first caregiving year; and (ii) estimate the extent to which caregiver characteristics and the functional profile of the care recipient impacts a caregiver’s emotional vitality in the first year.

Methods: Data came from an inception cohort of caregivers (n=409) that was followed over the first post-stroke year. Group-based trajectory modelling (GBTM), a form of latent class analysis, was used to identify distinctive groups of individuals with similar trajectories. Dual trajectories were used to estimate concordance between trajectories of emotional vitality and baseline health related characteristics of the caregiver (mastery, fatigue, social function, and mental health) and care recipient (stroke impact score).
Results: From the sample of caregivers (mean age 59 years, SD=14), five trajectories of emotional vitality were identified. Four trajectories maintained their baseline low emotional vitality level, and one showed deterioration over time. The largest group was the “low” group (38%) and has a baseline score of 17.9 that remained stable over time. Approximately 41% of caregivers with excellent mastery had the highest level of emotional vitality. No one with poor or very poor mastery had the highest trajectory of emotional vitality.

Conclusion: Emotional vitality in caregivers was on average very low in the first caregiving year. Mastery may be a component cause of emotional vitality, lending support to the importance of the need for health professionals to incorporate assessment of caregiver emotional vitality and mastery throughout the caregiving experience. Future work is needed to further test this association.
INTRODUCTION

Globally, the number of individuals over the age of 60 is expected to increase from 650 million to two billion by the year 2050.\textsuperscript{189} As a result, cardiovascular disease, specifically stroke, is expected to remain one of the leading causes of death and acquired disability.\textsuperscript{190} Post-stroke recovery has changed considerably in recent decades, with approximately 80\% of individuals returning home and rehabilitating in the community.\textsuperscript{9,24} Individuals who experience a stroke require considerable support from others to meet their daily needs. Up to 90\% of this assistance is provided by an unpaid family member, often an aging spouse with his or her own age-related infirmities.\textsuperscript{9,17,18,34} Stroke caregivers are required to quickly learn rehabilitation and medical management techniques, all while adjusting to changes in their relationships with the person who experienced the stroke. Unsurprisingly, stroke caregivers report high levels of stress and burden related to the deterioration of their own health status, social relationships, quality of life,\textsuperscript{12,15,25} and poor rehabilitation outcomes for the stroke survivor.\textsuperscript{25,191} Finding cost-effective ways to support caregivers is essential not just for the long term health of caregivers and care recipients, but also for the sustainability of the health care system itself.\textsuperscript{24,192}

There has been a recent call to revisit caregiver needs and the effectiveness of relevant interventions to improve support and service for family caregivers.\textsuperscript{24,183} To date, several caregiver interventions exist, however sufficient evidence for their effectiveness remains to be established.\textsuperscript{193} Caregiver intervention research
has been criticized for focusing on cross-sectional relationships between the provision of care and distress at specific points in time throughout the course of caregiving.\textsuperscript{194} It has also been highlighted that many studies lack a strong guiding theoretical and measurement framework relevant to caregivers to guide the evaluation of program effectiveness across caregiver populations.\textsuperscript{153} The result is a paucity of applicable information to guide efforts in identifying and supporting the needs of caregivers beyond the provision of information and advice regarding best care to the person who has experienced the stroke.\textsuperscript{153}

Emotional vitality is an emerging concept that describes the needs of an individual to maintain an overall sense of emotional well-being after a catalytic health event. Until recently, one of the limitations in understanding \textit{stroke caregiver emotional vitality} to has been a lack of a definition and measurement strategy to capture the construct. Recently, a theoretical and measurement model of emotional vitality for caregivers of people with stroke was proposed. The detailed methods and results of this concept analysis are reported elsewhere.\textsuperscript{145} In brief, caregiver emotional vitality is summarized as a latent construct consisting of five domains including: (1) physical energy and well-being, (2) mood, (3) mastery of new skills, (4) engagement in meaningful activity, and (5) support from others. From this concept analysis, methods outlined by Rasch Measurement Theory\textsuperscript{86,92} were used to develop an assessment measure of caregiver emotional vitality. The measure consists of 19 calibrated items that fit a hypothesized unidimensional linear model and meet the criteria for high quality, rigorous measurement with objective properties of order, magnitude and
invariance.\textsuperscript{65} The score from the emotional vitality measure is a quantity which is theoretically interpretable across time and sample populations, ideal for studying the emotional vitality of caregivers of individuals who have experienced a stroke. With a strong conceptual and measurement framework, it was not felt that emotional vitality and its relationship to health outcomes in caregivers and persons stroke could be studied.

Traditionally, longitudinal stroke caregiver data has been summarized by population means at serial time points for pre-defined groups (i.e. repeated measures Analysis of Variance (ANOVA)),\textsuperscript{182,195} measures of association between mean outcomes at various time points,\textsuperscript{25} and mean population growth curves and individual variations about these means.\textsuperscript{196} The assumption under these methods is that caregivers represent a homogenous group and behave in a similar fashion over time.\textsuperscript{194} One of the limitations of this approach is that summary means may be misleading, potentially missing the presence of distinct groups of individuals who behave differently across time.\textsuperscript{197} Trajectory analysis, or group-based trajectory modelling (GBTM), is a relatively new approach to modeling longitudinal data in health outcomes research. Introduced in the 1990’s, GBTM is used to estimate patterns over time and identify unobserved subgroups of individuals with similar trajectories.\textsuperscript{197} Specifically, GBTM identifies heterogeneous patterns of responding (or trajectory classes) that represent distinct populations.\textsuperscript{198} The shapes of the trajectories are useful pieces of information to guide subsequent analyses and aid in the interpretation of longitudinal validity.
This method of analyzing caregiver longitudinal data has important practical implications for health research and practice. GBTM can identify caregiver and care recipient characteristics that are associated with caregiver emotional vitality across time. Two studies have used these methods to model caregiver data thus far, one characterizing psychological distress patterns of family caregivers of individuals newly diagnosed with a malignant brain tumor\textsuperscript{194} and another reporting on the apathy of stroke caregivers.\textsuperscript{172} To our knowledge, this is the first study to use GBTM to study the emotional vitality of caregivers of stroke survivors. As well, this is the first study to use GBTM to model scores generated by a measure developed using Rasch Measurement Theory.

The overall aim of this study was to contribute to the understanding of the stroke caregiving experience by taking a longitudinal view of emotional vitality. The specific objectives were to estimate the extent to which (i) caregiver emotional vitality changes in the first caregiving year; and (ii) estimate the extent to which caregiver characteristics and the functional profile of the care recipient impacts a caregiver’s emotional vitality in the first year.

METHODOLOGY

Sample

Data for this study were drawn from a large study of health related quality of life of 678 Canadian stroke survivors and when possible their caregivers (n=409).\textsuperscript{156,172} Between 2003 and 2004, subjects were recruited from ten tertiary care centers in three Canadian cities: Montreal, (Quebec), Toronto (Ontario), and
London (Ontario). Caregivers were interviewed by telephone at 1, 3, 6, and 12 months after the stroke. Caregivers were eligible if they provided daily care for a person who experience a stroke and returned to the community, spoke English or French, and were able to provide informed consent. Caregivers were excluded if they had a severe co-morbidity that could dominate the pattern of care and result in serious health decline or death within the study period. The sample consisted of those caregivers who had data from at least two time points. Approval from at the institutional review board at McGill University was obtained for the original study.

Measures

Caregiver

Baseline caregiver demographic information included: gender, age, marital status, level of education, income, language, kin relationship to the stroke survivor.

Caregiver emotional vitality was measured using the prototype Emotional Vitality Measure (P-EVM) developed using Rasch Measurement Theory. The P-EVM is a self-reported outcome measure that consists of 19 items that reflect five domains of emotional vitality: energy (n=4); mood (n=6); mastery (n=1); engagement in meaningful activity (n=4); and support (n=4). As the data fit the underlying Rasch model, a meaningful total score can be derived from the sum of the caregiver responses to each item. The P-EVM has a range from 0 to 44, with higher scores indicating greater emotional vitality. The Rasch measurement psychometric criteria were supported: person separation index of 0.85 (indicating a stable person-item hierarchy); adequate scale-to-sample targeting; fit of the data to the
Rasch model ($\chi^2 = 202.26$, DF=117, $p=0.06$); and items spanning the range of the theoretical and measurement continuum.

Characteristics of the caregivers included baseline levels of personal mastery, energy/fatigue, pain, general mental health, and social participation. Baseline was defined as the first point of data collection (1 month post-stroke). Personal Mastery is the extent to which a person perceives himself or herself to be in control of events and ongoing situations. Personal mastery was measured using the 7-item Mastery Scale, which includes five negative items and two positively worded items. In this study, the response categories ranged from 1=strongly disagree to 4=strongly agree (the neither agree-nor disagree category was not asked); scores ranging from 7-28 with lower scores indicate a higher sense of mastery.

The other baseline characteristics were measured using four subscales from the RAND-36, a generic measure of perceived health status that incorporates behavioural functioning, subjective well-being and perceptions of health by assessing eight health concepts: (1) limitations in physical activities due to health problems; (2) limitations in role activities due to physical health problems; (3) pain; (4) limitations in social activities due to health problems; (5) general mental health; (6) limitations in usual role activities due to emotional problems; (7) vitality (energy & fatigue); and (8) general health perceptions. For the purpose of this study, we used the domains that covered pain, limitations in social activities, general mental health, and vitality.
Reliability, both test-retest and internal consistency, has been extensively demonstrated for the RAND-36, as have content, criterion and construct validity and responsiveness to clinical changes.\textsuperscript{157}

\textit{Care recipient}

Other explanatory variables included the care recipient’s demographic and clinical characteristics including age, gender, side of stroke, and type of stroke. The recovery and physical function profile was measured using the Stroke Impact Scale (SIS)\textsuperscript{200} and the RAND-36. The SIS is a 59-item disease-specific instrument that is used to assess eight domains, including hand function, strength, mobility, basic and instrumental activities of daily living, emotion, memory, communication ability, and social participation.\textsuperscript{103,200} Items are scored on a 5-point Likert scale, with scores of 5,4,3,2, and 1 corresponding to “not difficult at all”, “a little difficult”, “somewhat difficult”, “very difficult”, and “extremely difficult” respectively, with high scores indicating a greater degree of function. For the purposes of this study, scores have been transformed on a scale of 0-100. The SIS has established reliability and validity,\textsuperscript{200,201} and proxy-version of the SIS has also been validated against several well-known measures.\textsuperscript{202,203} The SIS also has undergone Rasch analysis testing, providing evidence that the scale is unidimensional and has items that have excellent range of difficulty, and scores that can differentiate individuals into different strata.\textsuperscript{103}

\textbf{Statistical Analysis}

Group-based trajectory modelling was used to identify distinctive groups of individuals with similar trajectories of emotional vitality over the first caregiver year. Our study used the model for censored normal data, with the calculated
emotional vitality score as an outcome regressed against the time from the start of caregiving (time from stroke). To model heterogeneity in caregiver emotional vitality we employed GBTM using the PROC TRAJ procedure in SAS 9.2 as a means to identify distinct growth trajectories and to test predictors of membership to these classes. For each caregiver, time-specific emotional vitality was plotted from the first time of assessment (one month post-stroke) to 12 months. Model selection was based on the iterative estimation of (1) the number of trajectory groups and (2) the shape/order of each trajectory group using both statistical and non-statistical considerations. Statistical criteria for ascertaining the best fitting model was determined using three criteria: Akaike’s Information Criterion (AIC), Bayesian Information Criterion (BIC), and the sample size adjusted BIC (ssBIC). The model with AIC, BIC, and ssBIC values closest to zero represented improvement over models with larger values. Concerning the BIC and the ssBIC, the prior treats time points as an observation and latter is based on the number of subjects. All fit statistics are given based on 1 degree of freedom per subject (rather than interview). Inspection of non-overlapping confidence intervals, sample size in each identified trajectory group, and inspection of the posterior probabilities across groups was also performed.

An advantage of using GBTM as a framework is that it very nicely characterizes change on the outcome variable and can also be used when predictor variables are also time-dependent. Dual trajectories can be used to estimate the prevalence of emotional vitality trajectories conditional on the trajectories of potential predictors.
Predictors of Emotional Vitality over Time

Variables related to the characteristics of the caregiver and the care recipient were tested for their relationship to emotional vitality over time. The candidate caregiver variables were: age, gender, marital status, highest level of education, income, kin relationship, baseline level of mastery, and baseline scores on the four domains of the RAND-36 (pain, vitality, mental health, and social function). The candidate care recipient variables were: side of stroke lesion (left, right, bilateral), and physical impact of stroke as measured by the SIS.

RESULTS

Sample

A total of 409 caregivers of people who experienced a stroke filled out the P-EVM. The majority of caregivers were women (n=268, 65.5%), university educated (n=234, 57.4%), and caring for spouses (n=255, 62.3%) and as a result the proportion of women among care recipients was 37.4%. Caregivers were on average younger than care recipients with a mean age of 58.5 years (SD=15.0; range 18-96) vs. 66.5 years (SD=14.6; range 19-97) for care recipients. Care recipients had a relatively equal distribution of side of temporal infarct (left=41.1%, right=45.5%). At time 1 (1 month post stroke), 384 caregivers filled out the P-EVM, at time 2 (3 months post stroke), 319 caregivers, time 3 (6 months post stroke) 292 caregivers, and time 4 (12 months post stroke) 278 caregivers. Of the 409 caregivers, 35 were lost by three months, half because of death or institutionalization of the care recipient and half because of unwillingness to
participate. The values on the P-EVM at baseline and other health related characteristics of the caregivers and care recipients are given in Table 6.1.

As shown in Figure 6.1 and Table 6.2, a five group trajectory model best fit caregiver emotional vitality over time. The P-EVM has a possible range of 0 to 44 and as shown in Table 6.1, the overall group mean was only 14.1 (SD=8.2). Thus, all groups would be considered to have lower than optimal emotional vitality. Four of five groups maintained their baseline low EV level, and one showed deterioration over time. Trajectory parameters are given in Table 6.3.

The largest group is the “low” group (38%) and has a score of 17.9 at baseline that remains stable, with no significant change over time. Three other groups also remain stable across time (very poor, moderate, moderate high). The “poor” group (33%) has an emotional vitality score of 13.7 that significantly decreases by 0.58 points per month.

Because the trajectories were essentially flat except for the one group which showed a small and likely clinically unimportant (based on $\frac{1}{2}$ SD rule) average decline of -0.23 units per month (2.76 units over 12 months), to screen for predictors we used a linear regression model with the emotional vitality score at three months post-stroke as the value to represent all time points as this had the largest number of subjects. As shown in Table 6.4, baseline level of mastery, caregiver general mental health, vitality, social, and care recipient stroke impact scores collectively explained 86% of the variance.

Predictors were measured on different scales and had different distributions, thereby making it difficult to directly compare relative impact of each on the outcome emotional vitality. Therefore, each beta value was standardized by
multiplying it by its (approximate) SD. The last column of Table 6.4 presents the results which shows that baseline fatigue (as measured by the Vitality domain of the RAND-36) had the greatest impact on emotional vitality per unit SD. In rank order of impact on emotional vitality were fatigue, mental health, mastery, social function, and stroke impact on care recipient. Of these factors, personal mastery is the one most amenable to rehabilitation intervention during the acute caregiving experience.

Figure 6.2 shows the trajectories of mastery considering that higher scores on the mastery scale indicate poorer mastery. Six trajectories best fit caregiver mastery over time; four were flat and two show monotonically increasing slopes reflecting decreasing mastery.

The prevalence of emotional vitality, conditional on the trajectories for mastery are shown in Table 6.5. Across the top of the table are the proportions of each of the emotional vitality trajectories, as shown in Figure 6.1. The second column represents the proportions within the trajectories of mastery, as shown in Figure 6.2. Within the body of the table are the conditional probabilities: the distribution across emotional vitality trajectories of caregivers conditional on mastery. Approximately 41% of caregivers with excellent mastery had the highest level of emotional vitality (considered moderately high given the range). However, this cell is very sparse (n=4). No one with poor or very poor mastery had the highest trajectory of emotional vitality. The greatest degree of concordance was between very good mastery and moderate emotional vitality (70.1%); also good and fair mastery with low emotional vitality (58.5% and 65.0%), and poor and very poor
mastery with poor emotional vitality (62.4% and 6.7%). Kappa for the association between mastery trajectory and emotional vitality trajectory was 0.45, considered fair with a 95% CI from 0.29 to 0.75, ranging for fair to good.

**DISCUSSION**

To our knowledge, this is the first study to explore emotional vitality among caregivers. Group based trajectory modeling was used to reveal distinct patterns that have not yet been discussed in stroke caregiver literature. Five distinct trajectories of caregivers were observed. All trajectories were stable over time, indicating that caregiver emotional vitality one month post stroke likely reflects caregiver emotional vitality one year post-stroke. This is of concern such that all trajectories started at relatively low levels. Given the range of the P-EVM is 0-44, all trajectories had baseline means that fell below a total score of 30, with 3 groups (representing approximately 78% of the sample) having mean baseline scores of less than 18. Other stroke caregiver studies have found that components of emotional vitality, including mood, energy, and mastery, are also persistently low over time.\(^{25,27,172,173,194}\) This suggests that the sample was fairly typical of the general stroke caregiver population.

Accepting the preliminary measurement properties of the P-EVM, the observation that EV did not change over time is both encouraging and discouraging. On one hand, it did not deteriorate which might be expected given the burden of care, but on the other hand it did not improve either, perhaps not surprising in the absence of any intervention.
Another important finding of this study was that baseline levels of caregiver mastery were associated with higher levels of emotional vitality. Previous studies have reported on strong associations between caregiver mastery and other variables such as depression and burden, independent of caregiver age, health status, and caregiving duration.\textsuperscript{14,26,194,206-208} We now ask the question is mastery a necessary and/or sufficient cause of emotional vitality? A cause is deemed \textit{necessary} if this factor always precedes the effect, or, in other words, if without this factor the outcome will not occur. A cause is \textit{sufficient} if, inevitably, the outcome will occur with this factor present.\textsuperscript{209} Outside of infectious disease, there are very few examples of necessary and sufficient causes in health; rather we recognize \textit{component causes} which collectively act to cause an effect.\textsuperscript{210} To address this, we took advantage of the longitudinal nature of the large caregiver data and identified trajectories of emotional vitality and other health related characteristics, over time. As mastery resulted as the most relevant predictor to caregiver emotional vitality, we used a dual trajectory approach to estimate the proportion of caregivers in each emotional vitality trajectory conditional on their trajectory of mastery. The assumption of this conditional approach was that, without evidence to the contrary, mastery precedes emotional vitality and is not a consequence of emotional vitality.\textsuperscript{211} The results show that mastery was neither a \textit{necessary} or \textit{sufficient} cause of emotional vitality, but would remain a \textit{component cause}.\textsuperscript{210} Not all caregivers with high emotional vitality reported high levels of mastery; and some caregivers with lower emotional vitality reported higher levels of mastery. This suggests that there are likely other factors must be present for a caregiver to have high emotional vitality. Considering our theoretical model of
emotional vitality outlined five key domains, it is possible that the other factors may include: (i) maintenance of physical energy and well-being, (ii) mood regulation, (iii) engagement in meaningful activity, and (iv) level of support for family and friends. Future work is needed to test the extent to which of these domains influences overall caregiver emotional vitality throughout the first year post-stroke.

Given the importance of maintaining caregivers in their roles, understanding how best to support this group is essential to inform systems of support. To date, existing interventions have been shown to have little or no effects in one of more areas including burden, knowledge level, mastering skills, and satisfaction. Existing clinical trials have been criticized for having poorly defined theoretical concepts and loosely developed programs, underscoring the importance of approaching future randomized, controlled designs from a different angle. Often the caregiver is considered a resource for the patient, not a separate entity in need of care and support. Our results support that this group is indeed languishing and in need of extra support. Emotional vitality may serve as a critical buffer against caregiver strain. Future work is needed to develop and test interventions that target the five domains of the complex construct.

This study highlights the potential for the mastery domain to be a modifiable target for intervention for caregivers. Caregivers are often provided with education, however ensuring they have full command of the new knowledge and skills is rarely addressed. In the field of education, mastery has been transformed into a learning strategy and quantified as the level an individual can attain when
he/she is able to correctly respond to 80% of questions on a test.\textsuperscript{199,213} There is much potential for health and rehabilitation professionals to learn how to apply key teaching and learning practices to promote mastery of caregivers. Educational and support programs are needed not only to provide caregivers knowledge about how to manage multiple competing demands and stresses associated with their efforts, but also to teach caregivers to take control of the most critical aspects of their lives, including their own wellness. An ideal intervention may include strategies to incorporate opportunities for ongoing education throughout the caregiving experience and a system of support to check on learning progress. Interventions that incorporate the key domains of emotional vitality may facilitate retention of family members in the caregiving role and potentially identify those who are at the greatest risk for inability to cope.

A key strength of this study is the use of an inception cohort of people with stroke to identify caregivers which reduces bias and strengthens generalizability to other stroke cohorts. The data set provided a large sample to measure the extent to which trajectories of emotional vitality are predicted by mastery, general mental health, fatigue, and social participation, while controlling for several caregiver and stroke patient variables. In addition, the larger sample allowed for five trajectories for emotional vitality to merge, and 6 trajectories for mastery. Currently, there is no accepted standard for calculating sample size for GBTM,\textsuperscript{214} but suggestions from similar studies exist.\textsuperscript{172,194} Mayo and colleagues\textsuperscript{172} found 7 trajectories with a sample size of n=634 individuals, whereas Choi \textit{et al.}\textsuperscript{194} found three trajectories with 103 individuals. Therefore, with the sample of 409
caregivers, the resulting number of trajectories groups for emotional vitality and mastery is justified.

Certain study limitations warrant comment. This study focused on a caregiver period that commenced at 1 month post stroke. Although this is the time period when the majority of patients are exiting the hospital, we are aware that the caregiving trajectory theoretically starts the moment a family member is admitted to hospital. It is also possible that factors related to emotional vitality may not have been included in the analyses (i.e., caregiver history of mental illness). In addition, the prototype measure needs further testing in a different sample of stroke caregivers and in caregivers of people with different health conditions. Further work needs to be done to identify if additional items would improve the measure. Tests of responsiveness to invention and longitudinal validity would be particularly important to carry out to support this construct as relevant to evaluating the caregiving experience.

**CONCLUSION**

Family caregiver efforts currently sustain the required system of support ensure stroke survivors can live at home in the community. Superficially, this is viewed as a cost effective approach to post-stroke management; however this contributes evidence that most stroke caregivers are languishing in their roles. A new approach to post-stroke management is needed to support both the care recipient and the caregiver. There is potential for this approach to include strategies to target emotional vitality and its domains, most specifically mastery.
### Table 6.1. Mean emotional vitality and health related characteristics of caregivers (n=409) and respective care recipients (n=409)

<table>
<thead>
<tr>
<th>Caregivers</th>
<th>Mean (SD)</th>
<th>Norms²¹⁵</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Vitality*</td>
<td>14.1 (8.6)</td>
<td>-</td>
</tr>
<tr>
<td>RAND-36 Domains†</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Role Physical</td>
<td>76.6 (37.7)</td>
<td>81.3</td>
</tr>
<tr>
<td>Role Emotional</td>
<td>74.3 (38.6)</td>
<td>87.8</td>
</tr>
<tr>
<td>Pain</td>
<td>78.0 (26.5)</td>
<td>74.9</td>
</tr>
<tr>
<td>Mental Health Index</td>
<td>73.2 (20.3)</td>
<td>79.5</td>
</tr>
<tr>
<td>Physical Function Index</td>
<td>85.7 (37.7)</td>
<td>84.3</td>
</tr>
<tr>
<td>Vitality</td>
<td>53.9 (24.7)</td>
<td>68.3</td>
</tr>
<tr>
<td>Global Health Perception</td>
<td>74.5 (19.8)</td>
<td>74.8</td>
</tr>
<tr>
<td>Social</td>
<td>77.0 (23.1)</td>
<td>88.1</td>
</tr>
<tr>
<td>Mastery††</td>
<td>22.8 (5.1)</td>
<td>-</td>
</tr>
</tbody>
</table>

| Care recipient     | Mean (SD)  | -         |
| Stroke Impact Scale| 64.7 (29.0)|           |

* Possible score range for P-EVM is 0-44, where higher scores are better;
† Possible score range for all RAND-36 domains is 0-100, where higher scores are better; ††Mastery measured using modified version of Mastery Scale (scoring range 7-28, where lower scores are indicative of higher mastery);
Note: norms refer to data from Canadian caregivers who are women aged 58 years old.
Table 6.2: Fit Indices for one to five-class growth models for Emotional Vitality (EV) and the one to six class growth models for Mastery (unconditional)

<table>
<thead>
<tr>
<th></th>
<th>Growth mixture model</th>
<th>1 class</th>
<th>2 classes</th>
<th>3 classes</th>
<th>4 classes</th>
<th>5 classes</th>
<th>6 classes</th>
<th>7 classes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>EV</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AIC</td>
<td>-1752.9</td>
<td>-1567.6</td>
<td>-1469.1</td>
<td>-1434.1</td>
<td>-1417.2</td>
<td>-1477.1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>BIC</td>
<td>-1768.1</td>
<td>-1598.0</td>
<td>-1514.8</td>
<td>-1495.0</td>
<td>-1493.3</td>
<td>-1505.9</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>SSBIC</td>
<td>-1764.8</td>
<td>-1591.5</td>
<td>-1505.0</td>
<td>-1482.0</td>
<td>-1477.1</td>
<td>-1414.6</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>Mastery</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AIC</td>
<td>-3377.4</td>
<td>-3206.9</td>
<td>-3147.3</td>
<td>-3129.8</td>
<td>-3119.3</td>
<td>-3109.3</td>
<td>-3105.7</td>
<td></td>
</tr>
<tr>
<td>BIC</td>
<td>-3392.6</td>
<td>-3237.3</td>
<td>-3192.9</td>
<td>-3190.6</td>
<td>-3195.4</td>
<td>-3200.5</td>
<td>-3212.1</td>
<td></td>
</tr>
<tr>
<td>SSBIC</td>
<td>-3377.4</td>
<td>-3230.8</td>
<td>-3183.2</td>
<td>-3177.6</td>
<td>-3179.1</td>
<td>-3109.3</td>
<td>-3189.4</td>
<td></td>
</tr>
</tbody>
</table>

Note: EV=Emotional Vitality; AIC= Akaike information criterion; BIC=Bayesian information criterion; SSBIC=sample size-adjusted Bayesian information criterion (n=400 for unadjusted; 238 for adjusted)
<table>
<thead>
<tr>
<th>Group</th>
<th>Membership N (%)</th>
<th>Intercept β (SE)</th>
<th>Slope β (SE)</th>
<th>Slope2 β (SE)</th>
<th>Predicted Score at 12 mo.</th>
<th>Posterior Probability Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>EV</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mod high</td>
<td>12 (2.9)</td>
<td>27.1 (0.6)</td>
<td>-</td>
<td>-</td>
<td>26.4</td>
<td>0.92 (0.12)</td>
</tr>
<tr>
<td>Moderate</td>
<td>74 (18.3)</td>
<td>21.8 (0.4)</td>
<td>-</td>
<td>-</td>
<td>20.9</td>
<td>0.83 (0.16)</td>
</tr>
<tr>
<td>Low (reference)</td>
<td><strong>154 (37.6)</strong></td>
<td><strong>17.0 (0.4)</strong></td>
<td>-</td>
<td>-</td>
<td><strong>15.9</strong></td>
<td><strong>0.88 (0.18)</strong></td>
</tr>
<tr>
<td>Poor</td>
<td>136 (33.2)</td>
<td>13.7 (0.5)</td>
<td>-0.23 (0.04)</td>
<td>-</td>
<td>12.5</td>
<td>0.83 (0.16)</td>
</tr>
<tr>
<td>Very Poor</td>
<td>33 (8.1)</td>
<td>6.5 (0.6)</td>
<td>-</td>
<td>-</td>
<td>7.0</td>
<td>0.90 (0.13)</td>
</tr>
<tr>
<td><strong>Mastery</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td>11 (2.7)</td>
<td>13.3 (1.0)</td>
<td>-</td>
<td>-</td>
<td>13.1</td>
<td>0.91 (0.11)</td>
</tr>
<tr>
<td>Very Good</td>
<td>53 (12.9)</td>
<td>17.2 (0.4)</td>
<td>-</td>
<td>-</td>
<td>17.8</td>
<td>0.77 (0.19)</td>
</tr>
<tr>
<td>Good</td>
<td>96 (23.5)</td>
<td>23.0 (0.4)</td>
<td>-</td>
<td>-</td>
<td>25.6</td>
<td>0.81 (0.10)</td>
</tr>
<tr>
<td>Fair</td>
<td>48 (11.8)</td>
<td>14.1 (1.1)</td>
<td>2.3 (0.4)</td>
<td>-0.1 (0.03)</td>
<td>23.1</td>
<td>0.77 (0.17)</td>
</tr>
<tr>
<td>Poor</td>
<td>169 (41.4)</td>
<td>25.1 (0.4)</td>
<td>0.6 (0.2)</td>
<td>-0.03 (0.01)</td>
<td>27.5</td>
<td>0.83 (0.18)</td>
</tr>
<tr>
<td>Very Poor</td>
<td>32 (7.7)</td>
<td>32.4 (0.8)</td>
<td>-</td>
<td>-</td>
<td>29.8</td>
<td>0.84 (0.17)</td>
</tr>
</tbody>
</table>

Note: The slope reflects the change per month; EVS scores range from 0-44, with a higher score indicating greater emotional vitality; Mastery Scale scores range from 7-28, with a lower score indicating greater mastery; reference indicates the reference group; - indicates not applicable.
Table 6.4: Linear regression of caregiver emotional vitality (n=409)

<table>
<thead>
<tr>
<th></th>
<th>Univariate Model</th>
<th>Multivariate Model</th>
<th>Standardized β (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>β (95% CI)</td>
<td>β (95% CI)</td>
<td></td>
</tr>
<tr>
<td><strong>Caregiver</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>0.01 (-1.63, 0.51)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Women</td>
<td>-0.01 (-0.85, 0.84)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Education</td>
<td>0.03 (-0.30, 0.36)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Income</td>
<td>0.33 (0.14, 0.50)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Children</td>
<td>-0.26 (-1.10, 0.69)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Mastery</td>
<td>-0.23 (-0.25, -0.11)</td>
<td>-0.35 (-0.44, -0.25)</td>
<td>-1.75 (-2.20, -1.25)</td>
</tr>
<tr>
<td>Mental Health</td>
<td>-0.10 (0.12, 0.07)</td>
<td>-0.14 (-0.14, -0.08)</td>
<td>-2.80 (-2.80, -1.60)</td>
</tr>
<tr>
<td>Pain</td>
<td>0.00 (-0.02, 0.01)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Vitality (fatigue)</td>
<td>-0.18 (-0.20, -0.16)</td>
<td>-0.17 (-0.19, -0.15)</td>
<td>-4.25 (-4.75, -3.75)</td>
</tr>
<tr>
<td>Social</td>
<td>0.00 (-0.02, 0.05)</td>
<td>-0.04 (-0.06, -0.01)</td>
<td>-0.92 (-1.30, -0.23)</td>
</tr>
<tr>
<td><strong>Care Recipient</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>0.02 (-0.07, 0.11)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Men</td>
<td>0.01 (-0.85, 0.84)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Type of Stroke</td>
<td>0.04 (-0.07, 0.05)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Side of Stroke</td>
<td>0.00 (-0.63, 0.61)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>SIS</td>
<td>-0.01 (-0.03, 0.00)</td>
<td>-0.02 (-0.03, -0.002)</td>
<td>-0.60 (-0.90, -0.06)</td>
</tr>
<tr>
<td><strong>Model</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P-value</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>-</td>
</tr>
<tr>
<td>Adjusted R²</td>
<td>0.87</td>
<td>0.86</td>
<td>-</td>
</tr>
</tbody>
</table>

Abbreviations: CI=confidence interval; β=beta. Note: Standardized beta ~ standard deviation for variables which hold in the final model (mastery=5; mental health=20; vitality=25; social=23; SIS=30.)
Table 6.5: Prevalence (%) of caregiver emotional vitality conditional on mastery (n=409)

<table>
<thead>
<tr>
<th>Mastery (%)</th>
<th>Line on graph (%)</th>
<th>Emotional Vitality trajectory over first year caregiving (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mod High (3.5%)</td>
<td>Moderate (18.4%)</td>
</tr>
<tr>
<td>Excellent</td>
<td>1 (2.7)</td>
<td>40.9</td>
</tr>
<tr>
<td>Very good</td>
<td>2 (12.9)</td>
<td>18.2</td>
</tr>
<tr>
<td>Good</td>
<td>3 (23.5)</td>
<td>1.3</td>
</tr>
<tr>
<td>Fair</td>
<td>4 (11.8)</td>
<td>3.9</td>
</tr>
<tr>
<td>Poor</td>
<td>5 (41.4)</td>
<td>0.0</td>
</tr>
<tr>
<td>Very Poor</td>
<td>6 (7.6)</td>
<td>0.0</td>
</tr>
</tbody>
</table>
Figure 6.1: 5-group trajectory model for emotional vitality over the first year after stroke.
Figure 6.2. 6-group trajectory model for mastery over the first year of caregiving.
CHAPTER 7: Summary of Results, Discussion, and Conclusion

7.1 Summary of Results

The overall objective of this thesis was to contribute to the understanding of the caregiving experience by taking a longitudinal view of a key construct “Emotional Vitality”. A discussion of the relevant findings has been integrated into each manuscript and will not be repeated here. However, to place this overall discussion into context, the most important findings will be reiterated briefly.

The studies presented in this thesis followed three phases of concept analysis: (i) construct investigation (Manuscripts 1, 2 & 3), (ii) construct measurement (Manuscripts 3 & 4), and (iii) construct impact and determinants (Manuscript 5).

In the Manuscript 1, the development of a preliminary theoretical model of emotional vitality was described. The proposed model integrated results from a scoping review of the literature and a Delphi mapping exercise to the ICF to support the existence four domains comprising of emotional vitality including: (1) physical health, (2) regulation of mood, (3) mastery, and (4) engagement in other roles and activities. Manuscript 2 validated these four domains in caregivers of people with stroke. In this study, caregivers also highlighted that support from family, friends, and health professionals was also important to caregiver emotional vitality. As a result, a fifth domain, (5) social support, was added to the working conceptual model of emotional vitality (See Figure 3.1). Manuscripts 1 and 2 highlighted that emotional vitality is clearly a concept for rehabilitation. At this point in concept exploration, it was thought that if indeed emotional vitality is
potentially modifiable and can contribute to achieving positive health outcomes, reliable and valid measurement was essential to further advancement.

In Manuscript 3, Rasch analysis was used as a method to subject the working theoretical model to deductive quantitative testing using Rasch analysis of a secondary data set of 107 items answered by caregivers of stroke survivors (in this sense, akin to a factor analytical approach). This study was not an attempt to develop a measure and test its psychometric properties. Rather, Manuscript 3 presents a thorough examination of how a set of items, from an existing data set, can fit together to reflect the theoretical model of emotional vitality. The results suggested the 23 items reflecting the emotional vitality construct could be mapped onto a unidimensional hierarchy covering the spectrum of measurement from low to high. However, of note was that the vast majority of items that mapped had one or more anomalies that warranted further investigation. Although much information was gleaned from the fit of the 23 items, a full analysis of all 107 items under consideration was produced. Information about item fit, person fit, response ordering, targeting, and construct validity was gathered and informed the selection of items to be used for the purposes of a measurement concept map, or blueprint, to be used in Manuscript 4. This study also highlighted the value of using a method such as Rasch analysis to understand the behavior of items and people in a study. Of the 107 items, most (88) did not have response options that were ordered as expected for the caregiver population. For example, for the 20 items from the CES-D that were included in the initial pool, caregivers responded unexpectedly to questions that were reversed ordered or positively worded. This
showed how Rasch analysis can be used as a method to fully understand the performance of items in the sample under investigation. Although the primary purpose of this study was to contribute further evidence towards an initial understanding the concept of caregiver emotional vitality, it was also an in depth source of information about the behavior of potential items to be used for the purposes of measurement.

Two Manuscripts (3 & 4) discussed ways to use items from a secondary data set that could capture both the theoretical model underpinnings of emotional vitality and the requirements for producing a strong total score. Manuscript 4 was clearly a more targeted and careful approach to develop a measure. The study used Rasch Measurement Theory (RMT) to guide the development of a 19 item prototype measure of emotional vitality for stroke caregivers (P-EVM), with supporting evidence for the measure’s content, structure, validity, and reliability for use to assess caregivers post-stroke. RMT was guided by an iterative process of selecting and testing items based on information gleaned from Manuscripts 1-3.

Armed with a sound conceptual model and measure with a strong total score, it was now appropriate to examine this construct in a preliminary way to see how it changed over time. In Manuscript 5, this measure was used to contribute to the understanding of the stroke caregiving experience by taking a longitudinal view of emotional vitality. The results of this study showed that caregiver emotional vitality was persistently low throughout the first year of
caregiving and that caregiver baseline levels of mastery had a notable impact on emotional vitality throughout the first year post-stroke.

This concluding section will discuss the salient parts of the thesis.

7.2 Discussion

For centuries, there has been acknowledgement that the way people feel in their minds could influence the way they respond in their body.\textsuperscript{137} However, only recently has attention turned toward understanding how emotional well-being influences recovery, adaptation, and health outcomes. Rehabilitation professionals recognize the complexity of treating individuals with chronic health conditions and disabilities. While the physical aspects of function have been well defined and measured in rehabilitation, addressing the emotional response to a catalytic life event has not been systematically addressed. Most health professionals have a unique knowledge of, and respect for, the individualized process of adapting to life changing events such as acquiring a chronic health condition or caring for someone with a disability. As the number of individuals with disabilities and chronic illnesses increases dramatically with the aging population, a multi-disciplinary approach is needed to support individuals whose life may have been altered by disease or disability.

This thesis outlines a new concept for rehabilitation: emotional vitality. Taken together, these results from this thesis suggest that emotional vitality is a multidimensional concept of importance to individuals interacting with health care systems. This thesis presents a working model for health professionals to use as a guide to understand emotional vitality in people with chronic health
conditions and their caregivers. Each part of the theoretical model is within scope of practice of many health care professions, including medicine, nursing, rehabilitation, and social work. As my professional clinical background is in occupational therapy, the role of this profession in the assessment and treatment of emotional vitality is now discussed.

7.2a Implications of Emotional Vitality for Occupational Therapy Practice.

The core values and beliefs of the Occupational Therapy profession underpin a perspective on occupational performance and patient-centered practice. Occupational performance refers to:

“the ability to choose, organize, and satisfactorily perform meaningful occupations that are culturally defined and age appropriate for looking after one’s self, enjoying life, and contributing to the social and economic fabric of a community” (p.30).  

Occupational therapists work with individuals to help them choose, organize, and perform occupations which people find useful or meaningful in a given environment. When living with a disability, or caring for a person who requires assistance, “meaningful” can become synonymous with “necessary”. In the context of caregiving, as highlighted in Manuscript 2, the focus of daily life may be consumed by responsibilities associated with providing service to the care recipient. Occupational therapists understand that health is more than just the absence of disease and is strongly influenced by having choice and control in everyday occupations. For this reason, the proposed model of emotion vitality for stroke caregivers in this thesis has significant potential for use and application to
the field. The next section will discuss the role of occupational therapy in each domain outlined in the theoretical model.

*Physical Energy and Well-being.* Most occupational therapy models of practice address the physical components of occupations, task, and activity. As early as the 1920’s, occupational therapists had a role promoting energy conservation techniques, activity analysis, graduated exercise, and prevocational training programs. After World War II, with an increase prevalence of physical disability and chronic health conditions, the scope of occupational therapy broadened to include the use of prosthetic and orthotic technology, and treatment areas included kinetics, adaptive devices and techniques, work evaluation and retaining, and grading activity to promote physical function. This was also a time where the required need for the “informal caregiver” became apparent. In today’s era, the role of occupational therapists in addressing physical dysfunction for people with chronic health conditions is far reaching and has shifted towards moving individuals towards independence and quality of life. This new target of treatment requires more than one ingredient. Often a key ingredient is the caregiver of the person who seeks occupational therapy services.

*Chapters 1-3* summarized the physical consequences of taking care of someone with a stroke. In *Manuscript 2*, the domain of physical energy and well-being was highlighted to be of utmost importance to caregivers. In the context of caregiving, physical energy and well-being are basic requirements to provide the level of care needed by the stroke survivor. In *Manuscript 2*, caregivers described feeling overwhelmed physically, in pain, and chronically fatigued. Occupational
Therapists have the potential to work with both the care recipient and their caregiver to help manage their daily activities so that energy and physical well-being are optimized. Characterizing the role of occupational therapy in stroke rehabilitation to include the ongoing assessment of the caregiver’s physical energy and well-being may enhance the caregiver’s physical well-being and decrease their likelihood for injury and burnout.

*Mood.* In stroke rehabilitation, occupational therapists play an important role in addressing the neurological and musculoskeletal limitations which interrupt or jeopardize an individual’s ability to carry out normal life roles associated with self-care, productivity, and leisure by assessing and treating the disability and disease-related impairments. However, attention on the psychological impact of the disability is also warranted, as it can significantly influence successful rehabilitation efforts. A comprehensive treatment approach to helping individuals maintain quality of life with a chronic health condition or disability mandates the incorporation of psychological strategies to help buffer the stress associated with the new health state and the caregiving experience. ⁷,⁸

Amongst healthcare professionals, occupational therapists have a unique knowledge of, and respect for, the individualized process of adapting to life with a chronic health condition or disability. The incorporation of stress and coping assessment and intervention into daily practice may further enhance occupational therapists’ potential impact on the lives of so many who seek occupational therapy services.
At the beginning of this work, the construct of emotional vitality was carefully considered as a target of importance for the field of rehabilitation. With impairments in mood often being the domain of specialization for psychology or psychiatry, the second study in Manuscript 1 used the ICF to identify categories in the Body Function chapter that reflected emotional vitality. Ten of the 19 categories were mapped back to a “mood” domain of the working model for emotional vitality. Considering the ICF is the predominant model of disability used in the world, this study highlights that mood is indeed a domain of relevance to rehabilitation.

Examples of other models for disability to map emotional vitality were considered including the medical model and social model. The medical model considers disability as a problem of the individual as a result of disability, whereas the social model views disability as a problem created by the social environment. The ICF was chosen as a theoretical model because it incorporates both of these paradigms and acknowledges that every human being can experience a decrement in health and thereby experience some degree of disability.\(^1\) In addition, the model accounts for impairments that are not easily recognized, such as emotional dysfunction and motivation. It was felt that using the ICF was important to ensure that these “hidden impairments” were included in our conceptual model of emotional vitality.

Although the ICF is the richest and most comprehensive collection of disability related-domains, a limitation of using such a model is that disability is reflected as a deprivation in functioning. In future work, when understand a
construct that is positive in nature, using models that focus on capability, rather than disability, might be useful. It is recognized that this is indeed a shift in thinking, however, with the lack of progress made thus far in understanding caregiver burden and how best to support this group, a new model for thinking may be warranted. An example of a capability model commonly used in occupational therapy is the Canadian Model of Occupational Performance and Engagement, which envisions health, well-being and justice as attainable through the attainment and engagement of meaningful occupation.\(^{218}\) Occupational therapists are uniquely trained to understand “impairment” beyond the limitations set by an illness, chronic health conditions, or new life role. Helping clients and their caregivers focus on their capability to achieve meaningful goals is a core value of the profession. The following section will elaborate on the other domains of the emotional vitality model and how they very much reflect a needed approach to thinking from the perspective or “capability” versus “disability”.

*Mastery, Engagement in Meaningful Activity, and Support.* For occupational therapy, the domains of mastery, engagement in meaningful activity, and support are highly amenable to rehabilitation in the context of living with, or preparing someone to take care of a person with, a chronic health condition. Occupational therapists have the skills to help individuals acquire the knowledge or skills to be successful in new life roles. Occupational therapy interventions focus on adapting the environment, teaching new skills, and advocating for the client and their family to increase participation in meaningful daily activities.
Rehabilitation, from the perspective of occupational therapy, is not about keeping people in the community, but rather about empowering people to become a part of the community. After assuming a caregiving role, too often “communities” and daily activity becomes confined to the walls of a home or medical rehabilitation facility. This case for imbalance between caregiving and life outside of the caregiving role was espoused by many caregivers in Manuscript 2.

Manuscript 5 summarized an overall low level of emotional vitality over time. Accepting the preliminary measurement properties of the P-EVM that resulted in Manuscript 4, the observation that emotional vitality did not change over time is both encouraging and discouraging. On one hand, it did not deteriorate which might be expected given the burden of care, but on the other hand it did not improve either, perhaps not surprising in the absence of any intervention. These results present an opportunity for occupational therapists to play a strong role in the development of new interventions focused on enhancing the emotional vitality of caregivers. This may include promoting life balance, engagement in meaningful activity, increased social participation, and the development and mastering of new skills related to caregiving. Through increased sense of personal mastery and life balance, it is possible that caregiver physical energy, mood, and overall emotional vitality can be improved. Future studies are needed to determine if each domain is a necessary, sufficient, or component cause of emotional vitality. In order to do this, a similar dual trajectory approach from Manuscript 5 can be used.
7.2b Implications for using the P-EVM in Occupational Therapy Practice

In previous studies, emotional vitality has been inferred from the absence of psychological symptoms such as depression and anxiety. However, the results from this thesis highlight that emotional vitality is about much more than regulation of mood alone. It is about a person’s ability to balance life roles and health, in spite of the challenges associated with the catalytic health or life event. This thesis summarized a method of measuring stroke caregiver emotional vitality. The measure that resulted in Manuscript 4 was developed with the guidance of Rasch Measurement theory and includes a set of items that are conceptually driven and produce a meaningful strong total score. Although the P-EVM is still in the preliminary stages of testing, the strength of this assessment tool is that it was developed using mixed methods, both qualitative and quantitative.

The approach to developing and testing patient-reported outcomes (PROs) has changed significantly in recent years. The inclusion of the patient, clinician, and other relevant stakeholders in the entire process of developing PROs. Prominent agencies including the United States Department of Health and Human Services Food and Drug Administration (FDA), emphasize that the development and evaluation of a PRO instrument is not a linear process. For approval by the FDA, a research group using a PRO in a trial must not only provide the clinical trial objectives and design, but also the targeted population, and the PRO instrument’s conceptual framework and “measurement properties”. As stated by the FDA, “Because of the purpose of a PRO is to capture the patient’s experience, an instrument will not be a credible measure without evidence of its usefulness for
the targeted population” (p.3). The content validity, conceptual framework, and documented PRO instrument development and testing for the targeted population are strongly encouraged when researchers subject an instrument to review by the FDA. This is a shift in thinking that encourages all researchers to ask the question “what is it that we are measuring?” and do we have the best tool to capture this construct? Meeting the criteria for “reliability and validity” may soon no longer be sufficient for large funding and approval organizations. Using the FDA once again as an example, the following characteristics of PRO instruments that are reviewed include:

- Concepts being measured
- Number of items
- Conceptual framework for the instrument
- Medical condition for intended use
- Population for intended use
- Data collection method
- Administration mode
- Recall period
- Scoring
- Weighting if items or domains
- Respondent burden
- Translation of cultural adaptation availability

The result of Manuscript 4 was the P-EVM which met most of the criteria noted above. The process was iterative, or a continuous cycle of understanding how best to represent a strong conceptual model by a set of items with strong measurement characteristics. The result is a preliminary measure that produces
score that are clearly interpreted for this population. This is important for knowledge translation and future research activity. Future work is needed to further test the P-EVM across different samples of stroke caregivers, in addition to other caregivers of people with chronic health conditions. This may require additional qualitative work with targeted samples of caregivers. Eventually, testing the translation of cultural adaptation availability of the tool will be needed if it is deemed an important tool for monitoring caregiver functioning over time.

In the near future, integrating the assessment of emotional vitality in daily practice using the P-EVM may enable occupational therapists to have a preliminary sense of the sources of stress in each domain that threaten the caregiving experience. Occupational therapists can use the results generated from the P-EVM to respectfully and gently engage caregivers in an ongoing dialogue about the changes experienced as a result of the caregiving experience and to monitor progress. The assessment may familiarize the occupational therapist with the caregiver’s perspective about the types of changes resulting from the new life experience, the personal meaning attached to these changes, and the potential impact on their day to day life. From this information, occupational therapists can work together with the caregivers to recommend specific coping strategies to enhance emotional vitality and overall quality of life.

7.2c Summary of the role of Occupational Therapy for Enhancing Caregiver Emotional Vitality.

Given the importance of maintaining caregivers in their roles, understanding how best to support this group is essential to inform systems of support. To date, existing interventions have been shown to have little or no
effects in one of more areas including burden, knowledge level, mastering skills,
and satisfaction.\textsuperscript{206,207} Existing clinical trials have been criticized for having
poorly defined theoretical concepts and loosely developed programs, underscoring
the importance of approaching future randomized, controlled designs from a
different angle.\textsuperscript{208,212} Often the caregiver is considered a resource for the patient,
not a separate entity in need of care and support. The results from this thesis
suggest preliminary evidence caregivers are indeed languishing and in need of
extra support. Emotional vitality may serve as a critical buffer against caregiver
strain and there is a clear role for occupational therapists to lead future work to
develop and test interventions that target the five domains of the complex
construct.

7.3 Strengths and Limitations of the thesis

A strength to this thesis was the use of modern psychometrics, specifically
Rasch Measurement Theory and Group Based Trajectory Modeling to measure
change over time. This allowed for the identification of distinctive developmental
paths in a complex longitudinal data set and meaningful interpretation of the paths
based on a strong total score.

Another strength was the use an existing data set of an inception cohort of
people with stroke and their caregivers. The analysis of data was an efficient and
ethical way to maximize the knowledge garnered from previous work and can be
used to justify the collection of new data to strengthen the knowledge base.
However, analysis of the secondary data may restrict generalizability. Although
this archived data provided rich material to be re-analyzed, the data was collected
for a specific purpose (understand health related quality of life of people with stroke and their caregivers) and not specifically understand caregiver emotional vitality. It would therefore be important to conduct further testing of the prototype measure on additional samples of caregivers and in other caring situations.

**7.4 Conclusion**

Many people as they age and if they develop serious health conditions such as stroke or cancer, become overwhelmed by the effects of new physical disabilities and may feel powerless to greatly modify the march of time and pathology on their functional capacity. However, emotional vitality may be a construct within their grasp and control and may in fact be a valuable target for psychosocial and rehabilitative interventions. The development of a preliminary conceptual and measurement model for emotional vitality that resulted from this work can help identify areas where interventions can be offered to improve the overall experience of living with, or caring for a person with, a chronic health condition or disability.

This thesis comprises of the first studies to explore emotional vitality among caregivers. The identification of domains relevant to emotional vitality in caregivers, and preliminary evidence for how this construct behaves over time, has important implications for healthcare treatment, delivery and policy. With the population increasing in age, the number of informal caregivers in developed countries is estimated to rise by about 75% in the upcoming decade.\(^26\) As one recent report noted “it’s not if, it’s *when* you will become a caregiver.”\(^24\) The
deinstitutionalization of care for individuals with chronic health conditions commands a much closer examination of the needs of this group. The model for emotional vitality in this thesis offers an initial platform to understand the complexity of the needs of caregivers and how to begin assessing and targeting them. The domains in this model also reflect priority areas outlined in recent calls of support for family caregivers. These reports highlight that successful caregiving is about much more than acquiring health information about the condition of a loved one. Previous caregiver research has focused on minimizing “strain” or “burden”, often outlining methods to minimize burnout and disability. The model presented in this thesis suggests that emotional vitality, in the context of the caregiving experience, is a comprehensive concept that health care professionals can approach from an angle of optimizing “capability” and well-being. The enhancement of caregiver emotional vitality, identification of those at risk for suboptimal coping, and development of targeted supportive interventions may facilitate successful adaptation of individuals living with chronic health conditions and the retention of satisfied family members in the caregiving role.

REFERENCES LIST


Lilly M. *Curtailing the cost of caring for employers and employees: what every CEO should know*. Ottawa: VON Canada;2010.


77. Weitzner MA, Jacobsen PB, Wagner J, H., Friedland J, Cox C. The Caregiver Quality of Life Index-Cancer (CQOLC) scale: Development
and validation of an instrument to measure quality of life of the family caregiver of patients with cancer *Quality of Life Research.* 1999;8:55-63.


82. Wright BD, Linacre JM. Observations are always ordinal; measurements, however, must be interval *Archives of Physical Medicine & Rehabilitation.* 1989;70:857-860.


114. Gallo LC, Bogart LM, Vranceanu AM, Matthews KA. Socioeconomic status, resources, psychological experiences, and emotional responses: a


163. Mayhew A, Cano SJ, Scott E, Eagle M, Bushby K, Muntoni F. Moving towards meaningful measurement: Rasch analysis of the North Star


ALPHABETICAL REFERENCE LIST


Davis, M.C. (2009). Building emotional resilience to promote health. *American Journal of Lifestyle Medicine, 3*(1), Suppl 60S-63S.


Tennant, A., & Conaghan, P.G. (2007). The Rasch measurement model in rheumatology: what is it and why use it? When should it be applied, and
what should one look for in a Rasch paper? *Arthritis & Rheumatism*, 57(8), 1358-1362.


Wright, B.D., & Linacre, J.M. (1989). Observations are always ordinal; measurements, however, must be interval *Archives of Physical Medicine & Rehabilitation, 70*, 857-860.