University of Wollongong Research Online

University of Wollongong Thesis Collection 1954-2016

University of Wollongong Thesis Collections

2007

The experiences of recovery from schizophrenia: development of a definition, model and measure of recovery

Retta Andresen PhD University of Wollongong, retta@uow.edu.au

Follow this and additional works at: https://ro.uow.edu.au/theses

University of Wollongong Copyright Warning

You may print or download ONE copy of this document for the purpose of your own research or study. The University does not authorise you to copy, communicate or otherwise make available electronically to any other person any copyright material contained on this site.

You are reminded of the following: This work is copyright. Apart from any use permitted under the Copyright Act 1968, no part of this work may be reproduced by any process, nor may any other exclusive right be exercised,

without the permission of the author. Copyright owners are entitled to take legal action against persons who infringe their copyright. A reproduction of material that is protected by copyright may be a copyright infringement. A court may impose penalties and award damages in relation to offences and infringements relating to copyright material. Higher penalties may apply, and higher damages may be awarded, for offences and infringements involving the conversion of material into digital or electronic form.

Unless otherwise indicated, the views expressed in this thesis are those of the author and do not necessarily represent the views of the University of Wollongong.

Recommended Citation

Andresen, Retta, The experiences of recovery from schizophrenia: development of a definition, model and measure of recovery, PhD thesis, School of Psychology, University of Wollongong, 2007. http://ro.uow.edu.au/theses/814

Research Online is the open access institutional repository for the University of Wollongong. For further information contact the UOW Library: research-pubs@uow.edu.au

NOTE

This online version of the thesis may have different page formatting and pagination from the paper copy held in the University of Wollongong Library.

UNIVERSITY OF WOLLONGONG

COPYRIGHT WARNING

You may print or download ONE copy of this document for the purpose of your own research or study. The University does not authorise you to copy, communicate or otherwise make available electronically to any other person any copyright material contained on this site. You are reminded of the following:

Copyright owners are entitled to take legal action against persons who infringe their copyright. A reproduction of material that is protected by copyright may be a copyright infringement. A court may impose penalties and award damages in relation to offences and infringements relating to copyright material. Higher penalties may apply, and higher damages may be awarded, for offences and infringements involving the conversion of material into digital or electronic form.

THE EXPERIENCE OF RECOVERY FROM SCHIZOPHRENIA: DEVELOPMENT OF A DEFINITION, MODEL AND MEASURE OF RECOVERY

A thesis submitted in fulfilment of the requirements for the award of the degree

DOCTOR OF PHILOSOPHY

from

UNIVERSITY OF WOLLONGONG

by

RETTA ANDRESEN B.Sc. (Hons)

School of Psychology

2007

DECLARATION

I, Retta Andresen, declare that this thesis, submitted in fulfilment of the requirements for the award of Doctor of Philosophy, in the School of Psychology, University of Wollongong, is wholly my own work unless otherwise referenced or acknowledged. The document has not been submitted for qualifications at any other academic institution.

Retta Andresen 30 October 2007.

ACKNOWLEDGEMENTS	vii
ABSTRACT	ix
INTRODUCTION	1
CHAPTER 1	
Recovery from Schizophrenia	7
1.1 Early conceptualisations of schizophrenia	7
1.2 Diagnostic systems and prognostic pessimism	. 10
 1.3 Empirical Evidence for Recovery	13 15
 1.4 The persistence of a pessimistic prognosis	21 22 23 24
1.5 The real possibility of recovery	. 26
1.6 Emergence of the "recovery" movement.1.6.1 What is meant by "Recovery"?	
1.7 Conclusion	. 33
CHAPTER 2 Study One: Formulating a consumer-oriented conceptual model and definition of recovery	
2.1 Need for a consumer-oriented model of recovery	. 35
2.2 Preliminary review of consumer literature	
2.2.1 Research questions of Study One	. 40
 2.3 Part 1: Describing and defining recovery in consumers' terms – a review of experiential literature. 2.3.1 Method	41 41 53 61
 2.4 Part 2: Identifying and describing the stages of recovery - A review of the qualitative research	63 63 71

TABLE OF CONTENTS

CHAPTER 3

Elaboration of the recovery model: Part I – The early phase	73
3.1 Stage 1 – Moratorium	
3.1.1 Hope: Hopelessness	
3.1.2 Responsibility: Powerlessness	
3.1.3 Identity: Loss of sense of self3.1.4 Meaning: Loss of purpose in life	
3.2 Conclusion	
5.2 Conclusion	91
CHAPTER 4	
Elaboration of the recovery model: Part II – The middle phase	93
4.1 Stage 2 – Awareness.	
4.1.1 Hope: The dawn of hope	
4.1.2 Responsibility: The need to take control	
4.1.3 Identity: I am not the illness4.1.4 Meaning: Need of a purpose in life	
4.2 Stage 3 – Preparation	
4.2.1 Hope: Mobilising resources4.2.2 Responsibility: Taking autonomous steps	
4.2.2 Responsibility: Taking autonomous steps	
4.2.4 Meaning: Reassessing goals	
4.3 Conclusion	
CHAPTER 5	110
Elaboration of the recovery model: Part III – the later phase	
5.1 Stage 4 – Rebuilding	
5.1.1 Hope: Active pursuit of goals	
5.1.2 Responsibility: Taking control5.1.3 Identity: Self-redefinition	
5.1.4 Meaning: Meaningful goals	
5.2 Risk, Perseverance and Resilience	
5.3 Stage 5 – Growth	
5.3.1 Hope: Optimism about the future5.3.2 Responsibility: In control of life and wellness	
5.3.3 Identity: An authentic self	
5.3.4 Meaning: Living a meaningful life	
5.4 Resilience, Stress-Related Growth and Finding Meaning	
5.5 Conclusion	
CHAPTER 6 Discussion of the stage model of recovery	155
6.1 The stage model of recovery from serious mental illness	
6.1.1 Other stage models of change6.1.2 Criticisms and contributions of stage models	
6.1.3 Issues surrounding the stage model of recovery	
6.2 Psychological recovery and positive psychology	
6.3 Conclusion	

CHAPTER 7

Study Two: Validity and feasibility of recovery-oriented outcome measurement	169
 7.1 Need for a stage measure of recovery	171 174 174 175 179
CHAPTER 8	107
Study Three: Development and testing of a stage subscale measure of recovery	197
8.1 The need for a more comprehensive measure of recovery8.1.1 Aims of Study Three	
8.2 Development of the Stages of Recovery Instrument (STORI)8.2.1 Generation of items	
 8.3 Pilot of the draft STORI and booklet of measures. 8.3.1 Method 8.3.2 Results 8.3.3 Refinement of the STORI 	199 202
 8.4 Testing the Stage of Recovery Instrument	206 209
CHAPTER 9	
Conclusions	223
9.1 The reality of recovery from schizophrenia	223
 9.2 A consumer-oriented definition and model of recovery 9.2.1 Common processes of recovery 9.2.2 Common stages of recovery 9.2.3 An integrated conceptual model of recovery 9.2.4 Implications of Study One 9.2.5 Limitations of Study One 	225 226 226 228
9.3 The validity of measuring recovery stage9.3.1 Implications of Study Two9.3.2 Limitations of Study Two	230 231
9.4 Development of the Stages of Recovery Instrument9.4.1 Implications of Study Three9.4.2 Limitations of Study Three and future research directions	233
9.5 Implications of the research for clinicians	235
9.6 Implications of the research for evaluation and research	
REFERENCES	239

APPENDIX A
Measures used in Study Two
APPENDIX B
Correlations between recovery measures and conventional clinical measures
APPENDIX C
Analysis of Variance examining effect of stage of recovery on clinical and recovery measures
APPENDIX D
The Draft STORI
APPENDIX E
Booklet of Measures used in Study Three
APPENDIX F
Analysis of Variance examining effect of STORI stage on recovery-related measures

List of Tables

Table 2.1. Summary of the consumer-based literature reviewed for Study One	38
Table 2.2. Concepts subsumed by each of the component processes.	54
Table 2.3 Comparison between recovery stages identified in five studies	71
Table 7.1. Descriptive statistics for total mean scores on all measures	180
Table 7.2. Spearman's correlations between recovery measures	180
Table 7.3 Spearman's correlations between conventional and recovery measures	182
Table 8.1 Questions on feedback forms for pilot study.	201
Table 8.2. Item themes table demonstrating process components across stages.	205
Table 8.3 Descriptive statistics of other well-being variables.	211
Table 8.4 T-tests comparing subscale means within each Stage-based group	213
Table 8.5. Pearson correlations between the item clusters and the other variables	214
Table 8.6 Means, standard deviations and intercorrelations of Stage subscales	215
Table 8.7 Pearson correlations between stage subscale scores and other	
variables	216

Table of Figures

Figure 7.1 Case clusters based on Z-scores on all measures for the four case clusters189

ACKNOWLEDGEMENTS

First I must thank the people who have struggled with mental illness and shared their stories of recovery with the world. These generous and courageous people provided me with the inspiration for my work, as well as the material for my research. I also thank the research volunteers who participated in my research, for giving their time and sharing their experiences to advance the understanding of recovery. The stories and experiences shared by people with a mental illness not only inspired my work, but also challenged me to dare to grow as a person. Any problem I encountered on my journey was insignificant compared to the challenges that they have faced and overcome.

I would like to thank my supervisors, Dr Lindsay Oades and Dr Peter Caputi of the University of Wollongong, for all their help and encouragement. I thank Lindsay especially for his creativity and conceptual discussions, and Peter especially for his statistical insights and for the benefit his experience. I thank both of them for their mentorship, for always being there when I needed them and for their belief in me. I feel that our relationship has grown into a sound research team over the years. I would also like to thank Professor Frank Deane for his support, his interest in my work and for providing a space for me to work within the Illawarra Institute for Mental Health. Thanks also to my fellow students and colleagues for their encouragement and support.

My family have been extremely important to me during my studies. I thank my parents, Martin and Janet Milroy, for their interest in my work, their pride in my achievements, and their unconditional love throughout my life. I also thank my children: Dave, Paul, Tony and Mandy for their love, support and understanding through my long years of study. Special thanks to Mandy, for her empathy, her creativity and especially her laughter, and for providing the musical soundtrack as we both worked. Also not forgotten is the love, interest and encouragement always shown by my brothers and sisters, near and far.

Most important has been the constant and steadfast support of my wonderful husband, John. I could not have completed my studies without his love, understanding, encouragement and practical support. The bountiful love of all my family is the greatest gift I could wish for in life.

viii

ABSTRACT

The traditional view of schizophrenia as having a deteriorating long-term course and an outcome of permanent disability has been challenged both anecdotally and empirically. Therefore, the consumer movement advocates that rehabilitation services become recovery-orientated. Recovery-oriented and empiricallyvalidated services have now become policy internationally. However, the meaning of *recovery* in a medical or research context is different than the meaning used by consumers. The objectives of this research were, therefore to (a) formulate a consumer-oriented definition of recovery; (b) develop a conceptual model of recovery to guide research and evaluation and inform clinical practice; (c) design a measure of recovery, based on the model, and (d) to seek empirical support for the model of recovery.

Study One involved a review of the consumer-oriented literature on the concept of recovery, with four aims: (a) to understand the meaning of recovery used by consumers; (b) to identify the components of recovery; (c) to formulate a definition of recovery; and (d) to define the stages of recovery. An examination of consumers' experiential accounts produced a definition of *psychological* recovery from the consequences of the illness. Four key processes were identified: (i) finding hope; (ii) re-establishment of identity; (iii) finding meaning in life; and (iv) taking responsibility for wellness and life generally. Five stages were synthesized from the extant qualitative research: (i) moratorium; (ii) awareness; (iii) preparation; (iv) rebuilding and (v) growth. A model of four processes developing over five stages is discussed in the light of the wider literature surrounding recovery from loss and the positive psychology literature. It is concluded that the philosophies of the positive psychology movement have much to offer in recovery-oriented approaches to treatment and research.

In Study Two, a brief measure, the Self-identified stage of recovery (SISR), was designed in order to test the model. The aims were to (a) test the validity of the stage measure against continuous recovery measures; (b) to test the notion of

recovery assessment as opposed to conventional measures of outcome, and (c) to seek support for the stage model of recovery. The SISR was completed by a clinical population participating in a larger study. High correlations between the recovery measures ($r_s = .262$, p = .01 to $r_s = .712$, p = .01) supported the validity of the SISR, while the pattern of correlations between the recovery measure subscales supported the validity of the SISR as a measure of level of recovery. Negative to low correlations between recovery and conventional measures ($r_s = .375$ to $r_s = .191$) supported the divergent validity of recovery as an outcome as distinct from conventional measures. In addition, an effect of stage was found on one conventional measure ($F_{(4, 127)} = 2.9$, p < .05) and all recovery measures ($F_{(4, 141)} = 2.87$, p < .05) to $F_{(4, 141)} = 4.68$ (p < .001), lending support to the stage model of recovery.

The aims of Study Three were to (a) produce a longer, more reliable measure that would better capture the richness of the experience of recovery; (b) examine the validity and reliability of this measure; and (c) seek further support for the stage model of recovery. The Stages of Recovery Instrument (STORI) consists of 50 items, each representing a psychological process at a stage of recovery. The STORI yields five stage subscale scores.

A postal survey of volunteers revealed that the STORI correlated with six psychological health variables (r_s = 0.45 (p < .01) to $r_s = 0$.62 (p < .01). Correlational analysis provided support for an ordinal relationship between the stage subscales. An effect of stage was found on all recovery-related variables, ($F_{(3,110)} = 10.70$ (p < .01) to $F_{(3,111)} = 24.44$ (p < .01). However, a cluster analysis of items resulted in three subscale clusters, rather than the expected five, revealing an overlap between adjacent stages.

The results provide preliminary empirical validation of the STORI as a measure of the consumer definition of recovery. Although an effect of stage was found, refinement of the measure is needed to improve its capacity to discriminate between the stages. It could then be used in comprehensively testing the stage model using longitudinal methods and the inclusion of objective measures. The concept of recovery elucidated in this research underlines the importance of taking a positive stance to recovery, focusing on values, meaning and growth rather than on illness-focused approaches to care. The five-stage model has proven useful in clinical training and as a framework for research into recovery. Validation of the model with longitudinal research is planned. Further development of the STORI is underway in separate research, and when refined, the measure should provide an outcome assessment tool that is meaningful to consumers and a useful adjunct to conventional clinical measurement.