

Carers' experiences of seeking help for relatives with first-episode psychosis: a systematic review of qualitative evidence

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Table of contents

LIST OF FIGURES	V
LIST OF TABLES	V
ABSTRACT.....	VI
DECLARATION	VIII
ACKNOWLEDGEMENTS	IX
CHAPTER 1: INTRODUCTION TO THE THESIS.....	1
PERSONAL INTEREST IN THE TOPIC.....	1
BACKGROUND.....	2
RESEARCH METHOD	2
OBJECTIVES	3
THE STRUCTURE OF THE THESIS	3
CHAPTER 2: BACKGROUND	5
INTRODUCTION.....	5
FIRST-EPISODE PSYCHOSIS	5
EARLY INTERVENTION FOR FIRST-EPISODE PSYCHOSIS.....	7
PATHWAYS TO CARE FOR FIRST-EPISODE PSYCHOSIS	9
OVERVIEW OF THE LITERATURE	10
RESEARCH METHOD	10
DEFINITION OF TERMS.....	11
CONCLUSION	12
CHAPTER 3: METHODOLOGY AND METHODS.....	13
INTRODUCTION.....	13
SYSTEMATIC REVIEW METHODOLOGY.....	13
REVIEW METHOD	15
<i>Objectives</i>	15
<i>Inclusion criteria</i>	16
<i>Search strategy</i>	17
<i>Method of appraisal</i>	18
<i>Data collection</i>	20
<i>Data synthesis</i>	20
CONCLUSION	21

CHAPTER 4: RESULTS	22
INTRODUCTION.....	22
DESCRIPTION OF STUDIES.....	22
METHODOLOGICAL QUALITY	25
RESULTS OF METASYNTHESIS OF QUALITATIVE RESEARCH FINDINGS.....	28
<i>Synthesised Finding 1</i>	28
<i>Synthesised Finding 2</i>	43
<i>Synthesised Finding 3</i>	54
<i>Synthesised Finding 4</i>	62
<i>Synthesised Finding 5</i>	72
CONCLUSION	88
CHAPTER 5: DISCUSSION	89
INTRODUCTION.....	89
ILLNESS RECOGNITION.....	90
HELP-SEEKING	91
SERVICE RESPONSE	92
IMPACT ON RELATIVES.....	93
COMMONALITIES AND DIFFERENCE	94
CONCLUSION	98
<i>Implications for practice</i>	99
<i>Implications for research</i>	100
<i>Implications for education</i>	100
<i>Implications for policy</i>	101
CONFLICT OF INTEREST	101
LIMITATIONS.....	101
REFERENCES	103
APPENDICES	112
APPENDIX I: SEARCH STRATEGY	112
APPENDIX II: APPRAISAL INSTRUMENTS.....	115
APPENDIX III: DATA EXTRACTION INSTRUMENTS	116
APPENDIX IV: LEVELS OF EVIDENCE.....	118
APPENDIX V: INCLUDED STUDIES	120
APPENDIX VI: EXCLUDED STUDIES.....	131

APPENDIX VII: LIST OF STUDY FINDINGS131

List of figures

FIGURE 1: FLOW DIAGRAM FOR RETREIVAL AND SELECTION OF STUDIES.....	23
FIGURE 2: MODEL DEPICTING THE INTERRELATED PROCESS INVOLVED IN CARERS' HELP-SEEKING.....	90

List of tables

TABLE 1: RESULTS FROM CRITICAL APPRAISAL.....	26
TABLE 2: SYNTHESISED FINDING 1.....	28
TABLE 3: SUMMARY OF EVIDENCE OF CREDIBILITY- SYNTHESISED FINDING 1.....	42
TABLE 4: SYNTHESISED FINDING 2.....	43
TABLE 5: SUMMARY OF EVIDENCE OF CREDIBILITY- SYNTHESISED FINDING 2.....	53
TABLE 6: SYNTHESISED FINDING 3.....	54
TABLE 7: SUMMARY OF EVIDENCE OF CREDIBILITY- SYNTHESISED FINDING 3.....	61
TABLE 8: SYNTHESISED FINDING 4.....	62
TABLE 9: SUMMARY OF EVIDENCE OF CREDIBILITY- SYNTHESISED FINDING 4.....	71
TABLE 10: SYNTHESISED FINDING 5.....	72
TABLE 11: SUMMARY OF EVIDENCE OF CREDIBILITY- SYNTHESISED FINDING 5	85

Abstract

Background

Individuals with a first-episode psychosis often have a prolonged and complicated path to accessing appropriate treatment. Research shows carers frequently initiate treatment though often delays remain even after problems have been detected. Qualitative studies have been conducted with the view to explore carers' experiences and inform the exploration of factors contributing to a long duration of untreated psychotic illness. Minimising the impact of psychosis for individuals and improving outcomes remain a priority in Clinical Practice Guidelines in many countries. Understanding and improving pathways to care is crucial to this goal.

Objectives

To synthesise the best available evidence on the lived experience of carers of a relative with a first-episode psychosis and in particular their experience preceding and of seeking help.

Inclusion criteria

Types of participants

Carers of a relative presenting with a first-episode psychosis. Carers could be a parent, sibling, spouse or other relative of any age.

Phenomena of interest

Carers' experience of a relative with a first-episode psychosis, and in particular their experience preceding and of seeking help from both informal (family and friends) and formal (services) sources.

Context

Research conducted in any mental health care setting in any country.

Types of studies

This review considered a wide range of qualitative studies including but not limited to designs such as phenomenology, grounded theory, ethnography and action research.

Search strategy

Published and unpublished studies in English from January 1990 to August 2012 were identified by searching various electronic databases.

Methodological quality

Papers selected for retrieval were assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardised critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI).

Data collection

Data was extracted from identified papers using the standardised data extraction tool from JBI-QARI. This included specific details about the phenomena of interest, populations, study methods and outcomes of significance to the review objectives.

Data synthesis

Research findings were pooled using JBI-QARI. Study findings were rated according to their quality, and categorised on the basis of similarity in meaning. These categories were then subjected to a meta-synthesis to produce a set of synthesised findings.

Results

Twenty-two studies were identified following appraisal that considered carers' experiences of help-seeking for a relative with a first-episode psychosis. Five synthesised findings were derived from 16 categories and 213 findings.

Delays often began at the stage of illness recognition. The main barriers to seeking help were fear of stigma and reluctance of the ill relative to participate in the process. A crisis and overt psychotic symptoms were the main promoters of active help-seeking and facilitators to accessing services. Service response was often viewed as a barrier to service access. A significant negative impact on carers of individuals with a psychotic illness was reported during the early stages of illness development, recognition, management and help-seeking, though the impact for each family member may differ.

Conclusions

Delays in accessing appropriate treatment arise at the illness recognition, help-seeking and service response stages. These areas were found to be interrelated. There was significant impact on carers throughout each of these stages.

Keywords

Help-seeking; Carers; First-episode psychosis; Qualitative, Systematic Review

Declaration

I, Suzanne Dawson, certify that this work contains no material that has been accepted for the award of any other degree or diploma in any University of any other tertiary institution, and, to the best of my knowledge and belief, contains no material previously published or written by any other person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint award of this degree.

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