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Tania Burns

St George Public Hospital, tb491@uowmail.edu.au

Ritin Fernandez

University of Wollongong, ritin@uow.edu.au

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Experiences of adults on dialysis and waiting for a renal transplant from a deceased donor: a systematic review protocol

Abstract

The objective of this systematic review is to synthesize qualitative evidence relating to experiences of adults with end stage renal failure who are on dialysis and waiting for a renal transplant from a deceased donor.

Disciplines

Medicine and Health Sciences | Social and Behavioral Sciences

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Experiences of adults on dialysis and waiting for a renal transplant from a deceased donor: a systematic review protocol

Tania Burns, RN, GCert Acute Care Nursing (Renal)¹

Ritin Fernandez, RN, MN (Critical Care), PhD^{2,3}

1 Clinical Nurse Consultant, St George Public Hospital, New South Wales

2 Professor of Nursing, University of Wollongong, New South Wales

3 Centre for Evidence Based Initiatives in Health Care: an Affiliate Center of the Joanna Briggs Institute

Corresponding author:

Tania Burns

tania.burns@sesiahs.health.nsw.gov.au

Review question/objective

The objective of this systematic review is to synthesize qualitative evidence relating to experiences of adults with end stage renal failure who are on dialysis and waiting for a renal transplant from a deceased donor.

Background

Chronic kidney disease (CKD) is a progressive, irreversible condition diagnosed on the basis of a reduced glomerular filtration rate (GFR), abnormalities in the composition of the blood or urine or abnormalities observed by imaging.¹ A diagnosis of CKD requires a GFR of <60ml/min/1.73m² and the presence of kidney damage for a period of at least three months.² CKD is categorized into five stages based on the GFR. Stage five CKD is also known as end stage renal failure (ESRF) and is said to occur when the GFR is <15ml/min/1.73m² and when renal replacement therapy (RRT) is required in order to support life.^{2,3} Treatment choices for RRT include hemodialysis (HD), peritoneal dialysis (PD) or kidney transplantation. Hemodialysis involves filtering the patient's blood across a semi-permeable membrane to remove toxins and excess fluid through combined use of diffusion and ultrafiltration.⁴ People receiving HD require the surgical creation of a vascular access⁵ and spend 12-24 hours per week connected to the HD machine.² Peritoneal dialysis uses the peritoneal membrane to remove toxins and excess fluid through use of diffusion and ultrafiltration.⁶ Patients require a permanent peritoneal access device⁷ and perform a number of fluid "exchanges" daily.⁸ Kidney transplantation involves surgically transplanting a donor organ and suppressing the immune response to the grafted organ with immunosuppressive medication.⁹ Kidney transplantation has been recognized as the best RRT in terms of morbidity, mortality and quality of life (QOL).^{10,11} At the end of 2012 it was estimated that over 150,000 people around the world were waiting for a kidney transplant.¹²

Donor organs for kidney transplant are available from either a living or deceased donor.⁹ The process of transplantation from either a living or deceased donor is protected with legislation including global agreements¹³ and national and regional laws.¹⁴⁻¹⁶ Some countries allow the pre-emptive listing of patients to receive a deceased donor transplant before they start dialysis, while others, including Australia, do not allow patients onto a waiting list until they have commenced dialysis.¹⁶ Because there are many more people waiting than there are available organs the waiting time is often prolonged for many years. However due to the nature of the organ allocation process it is possible, although rare, for a person to receive an organ after only a few months.¹⁷ The median waiting time for a kidney transplant from a deceased donor ranges from 3.1 to 4 years.^{17,18} With other solid organ transplants such as liver, heart or lung, people die if an organ does not become available; but with kidneys, dialysis is able to maintain the patient's life for many years.¹⁹

While it is positive that dialysis is available to keep a patient alive while waiting for a transplant, the length of time waiting on dialysis has been shown to impact both physical²⁰ and psychological aspects of QOL of patients.^{21,22} Limited quantitative data exists relating to people who are on dialysis and waiting for renal transplant from a deceased donor. Studies have looked at the effect of the length of time on dialysis before receiving a kidney transplant on the post transplant outcomes, and have found that increased time on dialysis is a strong independent risk factor for increased patient mortality and increased graft failure following renal transplantation.²³ People on dialysis have been shown to have multiple stressors in their lives, with depression considered as the most common psychiatric abnormality.²⁴ Meta-analysis of 52 studies reporting on QOL of people based on the different types of RRT indicated that scores of patients on dialysis (HD and PD) were lower compared to those with a functioning renal transplant.²⁵ Qualitative studies looking at the experience of waiting for a transplant have been carried out, but many are related to organs other than kidneys.²⁶⁻³² Transplantation of organs such as liver, heart and lung are lifesaving procedures and the experience of waiting is not the same as waiting for a kidney where life can be maintained indefinitely with dialysis. Studies examining the experiences of patients waiting for a transplant from a living donor^{33,34} are also not comparable because the donor is usually known to the recipient, either a relative or someone with an altruistic motive for donating³⁵, and the dynamics of the relationship between the donor and the recipient alters the experience of waiting.³⁶ Waiting for a transplant from a living donor is an active process with a finite goal; rather than the unclear, indefinite end point when waiting for a deceased donor.³⁷

Qualitative studies that have examined the experiences of people on dialysis who are waiting for a deceased donor renal transplant have identified themes of "living in hope", "uncertainty" and "being on hold".²¹ Anxious and depressive symptoms have been shown to increase in patients during the waiting period.²² Although some primary research has been conducted, these studies have not been systematically reviewed. The purpose of this review is to examine the existing evidence of patients' experiences of being on dialysis and waiting for a renal transplant from a deceased donor to underpin the development of effective supportive interventions.

Prior to commencement of this review a search was performed through the Joanna Briggs Institute (JBI) Library, The Cochrane Library, CINAHL, Medline and PsycInfo to ensure no previous systematic reviews had been done on the experiences of adult patients on dialysis waiting for a renal transplant from a deceased donor.

Keywords

Kidney/renal failure; kidney/renal transplant; quality of life; experiences; cadaveric transplant; qualitative; dialysis

Inclusion criteria

Types of participants

This review will consider studies that include adult patients who were aged 18 years and over when they started dialysis, in order to examine the experiences of adults rather than children or adolescents. It will only consider studies including people who are waiting for a renal transplant from a deceased donor and who have been on dialysis (HD or PD) for up to 15 years. The development of erythropoietin in the mid-1980's combatted the effects of the anemia associated with ESRF and considerably improved the QOL of people on dialysis.^{38,39} Around the same time, advances in immunosuppressive medication meant that transplantation became a feasible option with good outcomes for more people.⁴⁰ Therefore studies of people who have been on dialysis for up to 15 years will be included, because people who have been on dialysis for longer than 15 years may have had experiences that are not typical today.

This review will not consider patients under the age of 18 years, patients receiving dialysis for acute renal failure, patients waiting for a transplant from a living donor or people waiting for a pre-emptive transplant from a deceased donor.

Phenomena of interest

This review will consider studies that investigate the experiences of adults waiting for a renal transplant from a deceased donor. More specifically the impact of waiting for transplant on lifestyle, coping strategies and day to day living will be included.

Context

This systematic review will consider studies that involve adults with ESRF who are on either HD in a hospital, a satellite unit or at home, or on PD, and who are waiting for a kidney transplant from a deceased donor.

Types of studies

This review will consider studies that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research.

In the absence of research studies, other text such as opinion papers and reports will be considered.

Search strategy

The search strategy aims to find both published and unpublished studies. A three-step search strategy will be utilized in this review. An initial limited search of MEDLINE and CINAHL will be undertaken followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe articles. A second search using all identified keywords and index terms will then be undertaken across all included databases. Thirdly, the reference list of all identified reports and articles will be searched for additional studies. Studies published in English will be considered for inclusion in this

review. Studies published from 1985-2013 will be considered for inclusion in this review which reflects the advances in both dialysis and transplantation, as previously mentioned.

The databases to be searched include:

CINAHL (Cumulative Index to Nursing and Allied Health Literature) (1985 – 2013)

MEDLINE (Medical Literature Analysis and Retrieval System Online) (1985 – 2013)

Embase (Excerpta Medica Database)(1985 – 2013)

PsycINFO (Ovid)

Cochrane Database of Systematic Reviews

The search for unpublished studies will include:

ProQuest Dissertations and Theses

OpenGrey

Virginia Henderson International Nursing Library

New York Academy of Medicine

Initial keywords to be used will be:

Kidney/renal failure; kidney/renal transplant; quality of life; experiences; cadaveric transplant; qualitative; dialysis

A detailed search strategy has been reported in Appendix I.

The literature search will be carried out by a librarian at Wollongong University using the identified search terms. Separate search strategies will be carried out for each database and references will be entered into Endnote. All duplicate references will be removed.

Assessment of methodological quality

Papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) (Appendix II). Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

Data collection

Data will be extracted from papers included in the review using the standardized data extraction tool from JBI-QARI (Appendix III). The data extracted will include specific details about the phenomena of interest, populations, study methods and outcomes of significance to the review question and specific objectives.

Data synthesis

Qualitative research findings will, where possible, be pooled using JBI-QARI. This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation through assembling the findings rated according to their quality, and categorizing these findings on the

basis of similarity in meaning. These categories are then subjected to a meta synthesis in order to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice. Where textual pooling is not possible the findings will be presented in narrative form.

Conflicts of interest

There are no conflicts of interest for this systematic review.

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Appendix I: Search strategies

Medline search strategy

1. kidney failure.mp. or exp Renal Insufficiency/
2. peritoneal dialysis.mp. or exp Peritoneal Dialysis/
3. kidney transplantation.mp. or exp Kidney Transplantation/
4. Kidney Failure, Chronic/ or Renal Dialysis/ or haemodialysis.mp. or Kidney Diseases/
5. renal dialysis.mp. or exp Renal Dialysis/
6. waiting list.mp. or exp Waiting Lists/
7. (tissue and organ procurement).mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
8. quality of life.mp. or exp "Quality of Life"/
9. experienc\$.mp. or Social Support/ or Depression/
10. adaptation.mp. or Adaptation, Psychological/ or Adaptation, Physiological/
11. Attitude to Health/ or Attitude/ or Attitude to Death/ or attitude.mp.
12. uncertainty.mp. or exp Uncertainty/
13. life change events.mp. or exp Life Change Events/
14. self care.mp. or exp Self Care/
15. self concept.mp. or exp Self Concept/
16. self efficacy.mp. or exp Self Efficacy/
17. interpersonal relations.mp. or exp Interpersonal Relations/
18. activities of daily living.mp. or exp "Activities of Daily Living"/
19. 1 or 2 or 3 or 4 or 5 or 6
20. 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18
21. 19 and 20
22. limit 21 to (english language and humans and "all adult (19 plus years)")
23. limit 22 to ("qualitative (maximizes sensitivity)" or "qualitative (maximizes specificity)" or "qualitative (best balance of sensitivity and specificity)")

Embase search strategy

1. kidney failure.mp. or exp kidney failure/
2. peritoneal dialysis.mp. or exp peritoneal dialysis/
3. kidney transplant\$.mp. or exp kidney graft/
4. kidney failure.mp. or exp kidney failure/
5. renal dialysis.mp. or exp renal replacement therapy/
6. waiting list.mp. or exp hospital admission/
7. quality of life.mp. or exp "quality of life"/
8. society/ or experienc\$.mp. or follow up/
9. local adaptation/ or social adaptation/ or adaptation/ or adaptation.mp.
10. attitude to sexuality/ or social attitude/ or attitude to illness/ or attitude to death/ or attitude.mp. or attitude to health/ or attitude to life/ or attitude/ or attitude to change/ or attitude to disability/ or patient attitude/
11. Mishel Uncertainty in Illness Scale/ or uncertainty.mp. or uncertainty/ or Mishel Uncertainty in Illness Theory/
12. life change events.mp. or exp life event/
13. self care.mp. or exp self care/
14. self concept.mp. or exp self concept/
15. self efficacy.mp. or exp self concept/
16. interpersonal relations.mp. or exp human relation/
17. activities of daily living.mp. or exp daily life activity/
18. 1 or 2 or 3 or 4 or 5 or 6
19. 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17
20. 18 and 19
21. limit 20 to (human and English language and adult <18 to 64 years>)
22. limit 21 to ("qualitative (maximizes sensitivity)" or "qualitative (maximizes specificity)" or "qualitative (best balance of sensitivity and specificity)")

CINAHL search strategy

1. kidney failure
2. Renal Insufficiency
3. peritoneal dialysis
4. kidney transplantation
5. Renal Dialysis
6. haemodialysis
7. Kidney Disease
8. waiting list
9. quality of life
10. experience
11. adaptation
12. Attitude to Death
13. Attitude to Health
14. uncertainty
15. life change events
16. self care
17. self concept
18. self efficacy
19. interpersonal relations
20. activities of daily living
21. S1 or S2 or S3 or S4 or S5 or S6 or S7 or S8
22. S9 or S10 or S11 or S12 or S13 or S14 or S15 or S16 or S17 or S18 or S19 or S20
23. S21 and S22
24. S23 Narrow by Subject: - all adult

PsychInfo

- 1 exp "activities of daily living"/
- 2 ("activities of daily living" or ADL).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 3 exp Behavior/
- 4 (behavior* or behaviour*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 5 exp Cognition/
- 6 cognition.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 7 exp affective disorders/
- 8 mood*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 9 exp "Quality of Life"/
- 10 ("quality of life" or qol).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 11 exp interpersonal relationships/
- 12 "interpersonal relation*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 13 "social interaction*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 14 "social support*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 15 (wellbeing or "well being").mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 16 exp satisfaction/
- 17 exp Client Satisfaction/
- 18 satisfaction.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 19 stress*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 20 depress*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 21 exp adjustment/
- 22 psychologist*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 23 exp Emotions/
- 24 emotion*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 25 anx*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 26 exp Lifestyle/

- 27 ("life style" or lifestyle*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 28 exp Uncertainty/
- 29 uncertaint*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 30 exp death attitudes/
- 31 exp Health Attitudes/
- 32 attitude.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 33 experience*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 34 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33
- 35 exp organ transplantation/
- 36 ((kidney* or renal) and (transplant* or donor* or provider* or survivor*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 37 35 or 36
- 38 cadaveric.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 39 37 and 38
- 40 (kidney* or renal).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 41 35 or 40
- 42 exp tissue donation/
- 43 "unrelated donor*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 44 42 or 43
- 45 41 and 44
- 46 39 or 45
- 47 exp kidney diseases/
- 48 ("renal replacement therap*" or RRT or "dialysis patient*").mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 49 ((renal or kidney*) and dialysis).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 50 hemodiafiltration.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 51 (hemodialysis or HD).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 52 ("peritoneal dialysis" or PD).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 53 hemofiltration.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 54 47 or 48 or 49 or 50 or 51 or 52 or 53

- 55 "kidney failure".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 56 ("end stage renal" or "end-stage renal" or ESRF or ESRD).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 57 "chronic kidney".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 58 55 or 56 or 57
- 59 54 or 58
- 60 34 and 37 and 59
- 61 ("300" or "320" or "340" or "360" or "380" or "390").ag.
- 62 60 and 61

Cochrane Library

#1	MeSH descriptor: [Activities of Daily Living] explode all trees	3488
#2	"activities of daily living" or ADL	5596
#3	MeSH descriptor: [Behavior] explode all trees	43674
#4	behavior* or behaviour*	46843
#5	MeSH descriptor: [Cognition] explode all trees	6160
#6	cogniti*	25934
#7	MeSH descriptor: [Mood Disorders] explode all trees	8381
#8	mood*	8900
#9	MeSH descriptor: [Quality of Life] explode all trees	13007
#10	"quality of life" or qol	31258
#11	MeSH descriptor: [Interpersonal Relations] explode all trees	3707
#12	"interpersonal relation**"	1603
#13	"social interaction**"	672
#14	"social support**"	3413
#15	wellbeing or "well being"	5477
#16	MeSH descriptor: [Personal Satisfaction] explode all trees	373
#17	MeSH descriptor: [Patient Satisfaction] explode all trees	7896
#18	satisfaction	17684
#19	stress*	21813
#20	depress*	52675
#21	MeSH descriptor: [Adaptation, Psychological] explode all trees	3442
#22	psycholog*	58469
#23	MeSH descriptor: [Emotions] explode all trees	10387
#24	emotion*	7899
#25	anxi*	20388
#26	MeSH descriptor: [Life Style] explode all trees	2365
#27	"life style**" or lifestyle*	5086
#28	MeSH descriptor: [Uncertainty] explode all trees	75
#29	uncertaint*	8838
#30	MeSH descriptor: [Attitude to Death] explode all trees	101

- #31 MeSH descriptor: [Attitude to Health] explode all trees 21982
- #32 attitude 11676
- #33 experience* 39675
- #34 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 212836
- #35 MeSH descriptor: [Kidney Transplantation] explode all trees 3147
- #36 (kidney* or renal) and (transplant* or donor* or provider* or survivor*) 9940
- #37 #35 or #36 9940
- #38 cadaveric 692
- #39 #37 and #38 519
- #40 kidney* or renal 36166
- #41 #35 or #40 36166
- #42 MeSH descriptor: [Unrelated Donors] explode all trees 2
- #43 "unrelated donor*" 195
- #44 #42 or #43 195
- #45 #41 and #44 25
- #46 #39 or #45 542
- #47 MeSH descriptor: [Renal Replacement Therapy] explode all trees 7312
- #48 "renal replacement therap*" or RRT or "dialysis patient*" 1530
- #49 (renal or kidney) and dialysis 7982
- #50 hemodiafiltration 311
- #51 hemodialysis or HD 6993
- #52 "peritoneal dialysis" or PD 15327
- #53 hemofiltration 519
- #54 #47 or #48 or #49 or #50 or #51 or #52 or #53 28910
- #55 MeSH descriptor: [Kidney Failure, Chronic] explode all trees 3151
- #56 "end stage renal" or "end-stage renal" or ESRF or ESRD 1723
- #57 "chronic kidney" 1427
- #58 #55 or #56 or #57 4948
- #59 #54 or #58 30640
- #60 (#34 and #37 and #59) 1125

#61	MeSH descriptor: [Living Donors] explode all trees	265
#62	#60 not #61	1089
#63	MeSH descriptor: [Empirical Research] explode all trees	358
#64	"qualitative research" or "qualitative stud*"	1230
#65	"interpretive research" or "interpretive stud*"	1
#66	"critical research" or "critical stud*"	33
#67	"qualitative descriptive"	15
#68	"grounded theor*"	53
#69	"case stud*"	1740
#70	"action research"	209
#71	ethnograph*	101
#72	phenomenolog*	142
#73	#63 or #64 or #65 or #66 or #67 or #68 or #69 or #70 or #71 or #72	3373
#74	#60 and #73	31
#75	#62 and #73	28
#76	MeSH descriptor: [Waiting Lists] explode all trees	307
#77	MeSH descriptor: [Watchful Waiting] explode all trees	77
#78	wait*	5480
#79	#76 or #77 or #78	5480
#80	#60 and #79	88
#81	#62 and #79	88
#82	#74 and #79	15
#83	#75 and #79	15

Appendix II: Appraisal instruments

QARI appraisal instrument

JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

	Yes	No	Unclear	Not Applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	☐	☐	☐	☐
2. Is there congruity between the research methodology and the research question or objectives?	☐	☐	☐	☐
3. Is there congruity between the research methodology and the methods used to collect data?	☐	☐	☐	☐
4. Is there congruity between the research methodology and the representation and analysis of data?	☐	☐	☐	☐
5. Is there congruity between the research methodology and the interpretation of results?	☐	☐	☐	☐
6. Is there a statement locating the researcher culturally or theoretically?	☐	☐	☐	☐
7. Is the influence of the researcher on the research, and vice- versa, addressed?	☐	☐	☐	☐
8. Are participants, and their voices, adequately represented?	☐	☐	☐	☐
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	☐	☐	☐	☐
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	☐	☐	☐	☐

Overall appraisal: ☐ Include ☐ Exclude ☐ Seek further info. ☐

Comments (Including reason for exclusion)

Appendix III: Data extraction instruments

QARI data extraction instrument

JBI QARI Data Extraction Form for Interpretive & Critical Research

Reviewer Date

Author Year

Journal Record Number

Study Description

Methodology

.....

Method

.....

Phenomena of interest

.....

Setting

.....

Geographical

.....

Cultural

.....

Participants

.....

Data analysis

.....

Authors Conclusions

.....

Comments

.....

Complete

Yes ☐

No ☐

Findings	Illustration from Publication (page number)	Evidence		
		Unequivocal	Credible	Unsupported

Extraction of findings complete

Yes ☐No ☐