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Reid, Carol, Goodwin, Sally, Boys, Jennifer, Taylor, Bernadette, [Hall, Jenny](#), & Chang, Anne
(2008)

The effectiveness of interventions which promote self-management for people with End Stage Renal Disease undergoing haemodialysis.
JBI Library of Systematic Reviews, 5(10).

This file was downloaded from: <http://eprints.qut.edu.au/86600/>

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**Queensland Centre for Evidence-Based Nursing & Midwifery
and
Royal Brisbane and Women's Hospital**

Systematic Review Protocol

Title/Topic:

The effectiveness of interventions which promote self-management for people with End Stage Renal Disease undergoing haemodialysis.

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Background

Prevalence

End Stage Renal Disease (ESRD) is rapidly becoming one of the largest growth areas in chronic health globally. ESRD is described as an irreversible loss of kidney function to the point that the kidneys fail to support life. When this occurs, Renal Replacement Therapy (RRT) (dialysis or transplantation) is required. Currently 1.4 million patients are reported to be receiving RRT globally with the incidence of ESRD growing at approximately 8% annually. The growth of ESRD is reported at five times the rate of world population growth and not expected to level out in the near future. The forces behind this growth include the aging population, an increase in chronic disease burden, increasing life expectancies and increased access to RRT. In developed countries including Australia most patients with ESRD are offered RRT. Furthermore the burden of costs to meet the rising incidence and prevalence of ESRD is expected to increase substantially. In America for example, the direct cost of RRT is projected to reach \$USD 28 billion by 2010. A large investment is therefore required to promote effective management and care interventions such as self care for people with ESRD (1, 2).

Home and Satellite Haemodialysis

Internationally haemodialysis in a hospital is reported as the most expensive modality with costs per person per year between USD 55,000 to 80,000 compared to home haemodialysis USD 33,000 to 50,000. It is also important to note that Australia and New Zealand have the highest proportion of patients in the world receiving home haemodialysis hence reducing some of the cost burden associated with ESRD in these countries. However worldwide there is only 0.5% of all haemodialysis patients receiving home haemodialysis compared to 1.2 million dialysis patients being treated in 20,000 haemodialysis centres (1).

Home haemodialysis (HHD) requires self-management and is attended to predominately by the patient or their support person (3). It is physiologically better as the patient is able to dialyse longer or more frequently (4), there is better psychosocial support and it offers patients more control over their lives, thus improving their quality of life (QoL) (5). Satellite haemodialysis (SHD) also involves some self-management by the patients even though it is carried out in a hospital or community setting. As both HHD and SHD requires patients to be self managing, the patient, therefore recognised as the principle manager of their illness, enjoys increased autonomy over some aspects of their treatment, with less medical support provided(3).

Self Management for ESRD

Exploring self-management in ESRD is extremely important for patients as they encounter several challenges including ongoing symptoms, complex treatments and restrictions, uncertainty about life and a dependency on technology, all impacting upon their autonomy particularly after commencement of haemodialysis (2, 6). Self management is defined as “the patient’s positive efforts to oversee and participate in their health care in order to optimize health, prevent complications, control symptoms, marshal medical resources, and minimize the intrusion of the disease into their preferred lifestyles.” (7) p. 386 An important issue supporting self-management interventions for people with ESRD is the concept of adherence or compliance as it has been found that 33% to 50% of people are non adherent to their treatment. Furthermore several studies (quantitative and qualitative) have indicated that health

outcomes including adherence to treatment are much improved and costs reduced when patients are involved in managing their own chronic illness (2, 6).

Interventions Promoting Self-management

Self- Management Education

While it is acknowledged that education about ESRD is given to patients during short clinical interactions, generally patients are left to make their own day to day decisions, hence self-management for these people is unavoidable (6). It is reported also that to best manage the complexities of psychological and behavioural issues intrinsic to people with ESRD, ongoing collaborative care and self-management education is required (2, 8). Current patient self-management education programs aim at achieving long-lasting changes in behaviour (9-13). This intervention also improves patient adherence to their dialysis regime (including diet and fluid intake) (14-16) as unfortunately non-adherence to haemodialysis regimens can significantly impact on the patient's quality of life and overall health to the point of serious long-term consequences and mortality (4, 14, 17).

Psychosocial Support

Many haemodialysis patients suffer from depression, anxiety, fear of their disease and the limitations and stress it puts on their lives (18). Reports indicate negative changes often occur in patients' attitudes towards self-management of their haemodialysis. Patients can present as proud and autonomous in their ability to achieve self-care and then regress and stay passive in their treatment (19). In order to achieve self-management of haemodialysis, the patient must take a more active role in their treatment which can be achieved through therapies that promote behavioural and lifestyle changes (12). Psychological support is currently recommended for patients undertaking self-management of their haemodialysis treatment (11). A number of different interventions are available, including behaviour modification and cognitive behavioural therapy (CBT) (11, 12). An individualised approach to such treatment is recommended (20) with patient's responding positively from non-compliance, to being very empowered and self-managing (21).

Patients with extensive social support systems have also shown improved adherence to treatment thus improving QoL and reducing risk of mortality (22, 23). For self-managing patients to obtain optimal health outcomes, ongoing social support networks are required (22). Kimmel defines social support as "the perception that an individual is a member of a complex network in which one can give and receive affection, aid, and obligation"(23) p.1605). Family members, friends, pastors, acquaintances in the workplace, and medical personnel are all recognised as providers of social support and are important for the patient's adjustment to chronic and acute illness (22-24).

There are major benefits for patients who are self-managing their haemodialysis such as improved treatment adherence (14), QoL and physical wellbeing (25). However there is no current, clear or standard approach to practice, assisting and supporting patients towards self-management of haemodialysis. This systematic review will seek to establish best practice for the promotion of self-management of haemodialysis regimens for patients with end stage renal disease.

Objectives

This systematic review seeks to establish what best practice is for:

Interventions which promote self-management for patients with End Stage Renal Disease (ERSD) undergoing Haemodialysis.

More specifically, the review questions are:

- 1) Do education interventions improve self-management for patients with end stage renal disease?
- 2) Do psychosocial interventions such as Cognitive Behavioural Therapy, behavioural therapy or other counselling therapies and social support, improve self-management for patients with end stage renal disease?

Criteria for considering studies for this review

Types of Studies

This component of the review will consider randomised controlled trials (RCT's) that compare support interventions such educational, psychological and psychosocial supports with a control group (receiving no treatment or the other supportive treatments listed above).

In the absence of RCT's other research designs, non-randomised controlled trials and before and after studies, will be considered for inclusion in a narrative summary to enable the identification of current best evidence regarding support interventions for those with ESRD.

Types of participants

This component of the review will consider studies with:

- All adults over the age of 18 years
- Patients with end stage renal disease
- Undergoing haemodialysis

Types of interventions/Phenomena of Interest

All studies evaluating the following interventions will be considered for inclusion in the review such as:

Interventions which promote self management including:

- Education interventions.
- Psychosocial interventions such as cognitive behavioural therapy and other behavioural therapies, counselling and social support.

Types of outcome measures/anticipated outcomes

This component of the review will consider studies that include the following outcomes:

- Adherence with haemodialysis treatment,
- Depression and/or anxiety,
- Quality of life,
- Carer burnout,
- Social support
- Patient satisfaction
- Adverse events potentially attributable to the intervention or control treatment
- Cost effectiveness of home haemodialysis

Search Strategy for identification of studies

The review will consist of a search of published and unpublished literature in the English language. The following databases will be searched to identify keywords contained in the title and abstract and relevant MESH headings and descriptor terms.

Cochrane Database of Systematic Reviews in the Cochrane Library
Cochrane Central Register of Controlled (CENTRAL) in the Cochrane Library
CINAHL
Clinical Trial Databases
Medline (1966 to present)
EMBASE
PsycINFO (1966 to May 2007)
Web of Science

Reference lists of published studies and reviews will be scrutinised.

Individuals and organisations with an interest in ESRD and self-management research will be contacted to identify unpublished and ongoing studies relevant to the review

Dissertation abstracts will be searched for unpublished studies.

The search strategy will be limited to the following years 1966 to 2007.

Key search terms are shown in table 1 (see appendix1).

Methods of review

Critical Appraisal

Papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using the standardised critical appraisal instruments for the Joanna Briggs Institute System for the Unified Management, Assessment and Review of Information package (SUMARI) (Appendix 2). The studies will be categorised according to the level of evidence presented. Any disagreements that arise between the reviewers will be resolved through discussion with a third reviewer.

Data Extraction:

Data will be extracted from papers included in the review using standardised data extraction tools from the Joanna Briggs Institute System for the Unified Management, Assessment and Review of Information package (Appendix 3).

Data Synthesis

Where possible quantitative research study results will be pooled in statistical meta-analysis using Review manager software from the Cochrane Collaboration (Review manager V4.04). All results will be double entered. Heterogeneity will be assessed using the standard Chi-square and visual interpretation of the graphs. Significant heterogeneity will be assigned when the p value is less than 0.05. The type of data collected will determine the type of analytical approach used during synthesis. For example odds ratio will be used to summarise effect for dichotomous data, and weighted mean differences (for continuous data) and their 95% confidence intervals will be calculated for analysis. Where statistical pooling is not possible the findings will be presented in narrative form.

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25. Curtin RB, Mapes D, Schatell D, Burrows-Hudson S. Self-management in patients with end stage renal disease: Exploring domains and dimensions. *Nephrology Nursing Journal* 2005;32(4):389-395.

APPENDIX 1

Search Strategy – Medline

- 1 exp Kidney failure, chronic/
- 2 exp Renal failure
- 3 end stage renal disease
- 4 ESRD
- 5 chronic kidney disease
- 6 1 or 2 or 3 or 4 or 5
- 7 exp Hemodialysis units, hospital/
- 8 exp Hemodialysis, home/
- 9 exp Renal replacement therapy/
- 10 haemodialysis
- 11 RRT
- 12 hemodialysis
- 13 7 or 8 or 9 or 10 or 11 or 12
- 14 exp Social support/
- 15 exp Cognitive therapy/
- 16 exp Patient education/
- 17 exp Counseling/
- 18 exp diet therapy/
- 19 quality of Life therapy
- 20 nutrition
- 21 psychoeducation
- 22 counselling
- 23 supportive therapy
- 24 behavio*al therapy
- 25 CBT
- 26 psychosocial
- 27 psychological intervention
- 28 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
- 29 exp Quality of life/
- 30 exp Self care/
- 31 exp Self efficacy/
- 32 health related quality of life
- 33 self management
- 34 29 or 30 or 31 or 32 or 33
- 35 RANDOMIZED CONTROLLED TRIAL.pt.
- 36 CONTROLLED CLINICAL TRIAL.pt.
- 37 RANDOMIZED CONTROLLED TRIALS.sh.
- 38 RANDOM ALLOCATION.sh.
- 39 DOUBLE BLIND METHOD.sh.
- 40 SINGLE BLIND METHOD.sh.
- 41 or/35-40
- 42 ANIMALS/ not HUMANS/
- 43 41 not 42
- 44 CLINICAL TRIAL.pt.
- 45 exp CLINICAL TRIALS/
- 46 (clin\$ adj25 trial\$.ti,ab.
- 47 ((singl\$ or doubl\$ or trebl\$ or tripl\$) adj25 (blind\$ or mask\$)).ti,ab.
- 48 PLACEBOS.sh.
- 49 placebo\$.ti,ab.
- 50 random\$.ti,ab.

51 RESEARCH DESIGN.sh.
52 or/44-51
53 52 not 42
54 COMPARATIVE STUDY.sh.
55 exp EVALUATION STUDIES/
56 FOLLOW UP STUDIES.sh.
57 PROSPECTIVE STUDIES.sh.
58 (control\$ or prospectiv\$ or volunteer\$).ti,ab.
59 or/54-58
60 59 not 42
61 43 or 53 or 60
62 6 and 13 and 28 and 34
63 61 and 62

APPENDIX 2

The Joanna Briggs Institute Critical Appraisal of Evidence of Effectiveness

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

1. Was the assignment to treatment groups random?
yes no not clear NA
2. Were participants blinded to treatment allocation?
yes no not clear NA
3. Was allocation to treatment groups concealed from the allocator?
yes no not clear NA
4. Were the outcomes of people who withdrew described and included in the analysis?
yes no not clear NA
5. Were those assessing the outcomes blind to the treatment allocation?
yes no not clear NA
6. Were control and treatment groups comparable at entry?
yes no not clear NA
7. Were groups treated identically other than for the named interventions?
yes no not clear NA
8. Were outcomes measured in the same way for all groups?
yes no not clear NA
9. Were outcomes measured in a reliable way?
yes no not clear NA
10. Was there adequate follow-up of participants? (>80%)
yes no not clear NA
11. Was appropriate statistical analysis used?
yes no not clear NA

Overall appraisal: Include Excluded Seek further info

Comments (including reasons for exclusion): _____

APPENDIX 3

**Joanna Briggs Institute
Data Extraction Form (Quantitative Data)**

Author Record Number

Journal

Year

Reviewer

Method _____

Setting _____

Participants _____

Number of Participants

Group A Group B

Interventions

Intervention A _____

Intervention B _____

Outcome Measures

Outcome Description	Scale/Measure

Results

Dichotomous Data

Outcome	Treatment Group Number/total number	Control Group Number/total number

Continuous Data

Outcome	Treatment Group Mean & SD (number)	Control Group Mean & SD (number)

Authors Conclusion

Reviewers Conclusion
