ELSEVIER

Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou



Mini-review

Behavioural research in patients with end-stage renal disease: A review and research agenda

Ad A. Kaptein ^{a,*}, Sandra van Dijk ^a, Elizabeth Broadbent ^b, Louise Falzon ^c, Melissa Thong ^d, Friedo W. Dekker ^d

- ^a Unit of Psychology, LUMC, Leiden, The Netherlands
- ^b Psychological Medicine, University of Auckland, Auckland, New Zealand
- ^c Cochrane Behavioral Medicine Field, New York, USA
- ^d Department of Clinical Epidemiology, LUMC, Leiden, The Netherlands

ARTICLE INFO

Article history: Received 15 May 2009 Received in revised form 3 September 2009 Accepted 25 October 2009

Keywords:
End-stage renal disease
Review
Research agenda
Psychosocial research
Evidence-based behavioural medicine
Disease-management

ABSTRACT

Objective: To suggest a behavioural research agenda for patients with end-stage renal disease (ESRD) based on a concise review of seven stages of psychosocial research, a literature review, and current behavioural research in other chronic somatic diseases.

Methods: Historical behavioural ESRD research was classified. The specialized register of the Cochrane Behavioral Medicine Field was also checked, and additional papers were selected by screening reference lists and related behavioural science journals, to identify promising areas for future research.

Results: The top-five topics identified via the literature search pertain to (1) psychological aspects and interventions, (2) adaptation, coping, and depression, (3) exercise, (4) counseling and education, and (5) compliance. 'Illness and treatment beliefs', 'sexuality', 'suicide', 'family support', and 'self-management interventions', were identified on the basis of research in other chronic illnesses as topics for future research. Regarding theory, the Common-Sense Model (CSM) was judged to offer useful theoretical perspectives; regarding methods, qualitative methods can be a valuable addition to quantitative research methods.

Conclusion: Illness beliefs, treatment beliefs, and self-management behaviours are promising concepts in the assessment and clinical care of ESRD-patients. Cognitive-behavioural treatments appear to have potential and should be specified and elaborated for specific categories and problems of ESRD-patients. Practice Implications: This research agenda is in line with moves towards patient-centred disease-management to improve the quality of medical care for ESRD-patients.

© 2009 Elsevier Ireland Ltd. All rights reserved.

1. Introduction

End-stage renal disease (ESRD) is the term used when renal replacement therapy is required because the kidneys cease to function permanently, in most cases as a consequence of another underlying physical disorder (e.g., diabetic nephropathy, hypertensive nephrosclerosis) [1–3]. ESRD affects some two million patients worldwide. It may result in the build-up of toxins and fluid in the body, hypertension, and a low red blood cell count. Transplantation is the most effective renal replacement therapy. Given the very limited availability of organs for transplantation and the possibility of rejection, other methods of medical

E-mail address: a.a.kaptein@lumc.nl (A.A. Kaptein).

management of ESRD are often indicated. Dialysis is an artificial way of filtering blood with the aim of removing toxins and excess fluids from the blood. In haemodialysis (HD) the blood is purified by an external artificial kidney machine. Patients usually spend 3–4 h, 3 days a week, on haemodialysis. In peritoneal dialysis (PD) the peritoneal membrane functions as an artificial kidney, where patients themselves are taught to fill and drain the abdomen with a dialysis solution via a catheter, usually in their own homes.

The tasks that face someone who lives with ESRD, especially when on dialysis therapy, appear overwhelming to the observer. Being connected to a haemodialysis machine three times a week for years in a row, or connecting oneself to a peritoneal dialysis system implies having to cope with major stressors, including the symptoms of ESRD, and the associated burden regarding social and societal consequences as additional adaptational tasks. Patients are often confronted with limitations in food and fluid intake, with symptoms such as itching and lack of energy, with psychological

^{*} Corresponding author at: Unit of Psychology, Leiden University Medical Centre, LUMC, PO Box 9600, 2300 RC Leiden, The Netherlands. Tel.: +31 71 526 2905; fax: +31 71 524 8123.

stressors such as loss of self-concept and self-esteem, feelings of uncertainty about the future, feelings of guilt towards family members, and problems in the social domain. In reviews, the issue of adherence with fluid restrictions and with the therapeutic regimens for HD and PD is identified as a major problem [2]. Increasingly, the social and behavioural consequences of suffering renal disease are being examined by behavioural scientists, usually in close collaboration with physicians, nurses, social workers and other health care providers [4]. This collaborative work has resulted in a body of knowledge on the topic of renal diseases and psychology as applied to medicine [5].

The number of publications on the subject "ESRD and psychology" is relatively low compared to the number of publications on, for example, cardiovascular disorders and psychology, or cancer and psychology. A PubMed literature search [29 August 2009] on 'end-stage renal disease and psychology' produced 2562 hits, while a similar search on 'cancer and psychology' resulted in 35,204 hits, and 'cardiovascular disorders and psychology' in 28,280 hits. We identified only two Cochrane reviews on 'renal dialysis and psychology': on psychosocial interventions for depression, and physical measures for treating depression in dialysis patients, respectively [6,7]. The lower prevalence of ESRD compared to cardiovascular disorders and cancer most likely is one explanation for this finding. Another possibility for the disparity may be unfamiliarity among nephrologists and other providers of medical care with the potential contribution of behavioural research and its ramifications for patient care to the well being of ESRD-patients.

This paper aims to provide the reader with suggestions for a research agenda for behavioural research with patients who have ESRD. Other authors have published research agendas for other categories of patients [8,9]. This agenda could be helpful in informing the future design of research lines in ESRD and aid funding decisions.

Defining a research agenda can be done via various strategies: focus group interviews where patients define research priorities based on their personal experiences with and views on care [8], comparing patients' experiences of services against objectives defined by health authorities and policy makers [10], identifying research priorities among a set of health care providers [11,12], or identifying gaps in the scientific knowledge of assessment and treatment of certain patient populations via literature searches [12–14]. This paper used the latter strategy. In addition, we provide an historical overview of behavioural research with ESRD-patients, giving illustrations of the successive research traditions identified in the research in the past 50 years in the field of psychology as applied to medicine [15,16]. More formal approaches in systematically reviewing literature and reporting meta-analyses are available (see e.g., QUORUM [17] and PRISMA guidelines [18]). Our aim, however, was to uncover research topics in a more qualitative manner which, in a next stage, may be subjected to these more formal methods of analyses.

2. Methods

2.1. Historical overview

Behavioural research on patients with ESRD was classified by looking at the history of empirical work in the area, starting around 1960 with the pioneering work by Levy [27]. The work was classified into the categories: (a) psychosomatic research, (b) neuropsychological research, (c) quality of life, (d) patient education, (e) coping and illness perceptions, (f) self-management, and (g) disease-management.

Two additional search strategies were applied to identify recent literature on psychological research with patients who have ESRD.

2.2. Systematic literature search

This was performed in a systematic way using a combination of subject headings and text words to represent ESRD-patients. This string was combined with an adapted version of the search strategy used by the Cochrane Behavioral Medicine Field to find behavioural intervention studies. The strategy is shown in Appendix A. Only empirical studies published in English in the vear 2000 or later were included. We limited the search to recent papers in order to keep the review manageable, and because we intended to base the recommendations on relatively recent work. Kidney transplant is of considerable interest to many patients as it saves them from the burden of dialysis therapy and improves their chances for survival. Furthermore, patients who have a successful kidney transplant have normal kidney function and significantly higher quality of life than those with ESRD [19]. The chronic nature and the many adaptive tasks associated with living with ESRD is the focus of our review. Therefore, while acknowledging the great importance of the topic of kidney transplant, we focused on haemodialysis and peritoneal dialysis; kidney transplant deserves a separate review.

2.3. Screening of related literature

Reference lists of papers in nephrology journals and journals in the behavioural sciences were screened, additional references were examined via 'snowballing', and the authors' files were screened for any other relevant papers [20–25]. From those files we selected papers, using the same criteria as in the first strategy, i.e., empirical papers in English published after 2000. We selected those papers that in our view broke new ground, used interesting methods, or applied modern and relevant health psychology theories. Cukor et al. [5] used this strategy as well to come up with a list of, in their view, high priority research topics. While acknowledging the somewhat subjective nature in this approach, it may be instrumental in suggesting areas additional to those identified in the formal literature search. Grey literature was not included as we only included papers in the PubMed database.

3. Results

3.1. Historical overview

Fig. 1 illustrates the seven approaches identified in behavioural research in ESRD-patients over the past 50 years. In the first approach, behavioural problems in ESRD-patients were viewed from a psychiatric perspective, which involved the use of psychiatric diagnostic labels and therapeutic methods. One of the first publications in this area is a paper where the author outlines the adaptive tasks that face someone who is undergoing repetitive dialysis [26]. Recently, Levy reviewed the area of what he labels "psychonephrology", exhibiting a life-long dedication to research on the psychological and psychiatric well being of ESRDpatients [27]. Behavioural researchers nowadays consider such a term as somewhat stigmatizing, and prefer concepts such as selfmanagement. A more recent study in this first approach is Drayer et al.'s longitudinal examination of mortality in haemodialysis patients as predicted by depression [28]. In the study the authors found a 28% prevalence of major or minor depression, with depression predicting mortality, controlling for sociodemographic and clinical characteristics. As a consequence, these authors state that the effects on mortality of treating depression in ESRDpatients must be studied.

Neuropsychological consequences of ESRD represent the second approach in the research history (Fig. 1). In 1990, Davis et al. used the Minnesota Multiphasic Personality Inventory

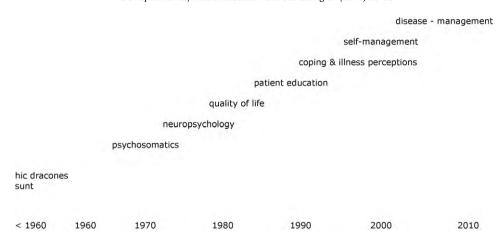


Fig. 1. Theoretical approaches to behavioural research and clinical care for patients with ESRD, 1960 to current.

(MMPI), a questionnaire that assesses psychiatric and neuropsychological deficits, in renal, psychiatric, and general medical patients [29]. They found elevated levels of impairments in both domains in renal patients. A recent study examined memory defects in patients on haemodialysis, illustrating how this research line is currently still being actively pursued [30].

Quality of life (QOL) is the third subject in the research history on psychosocial aspects of ESRD. With the first reference to QOL in 1966, scientists with a medical, nursing or behavioural background explored the impact of ESRD and its treatment on physical, psychological, and social functioning, as perceived by the patient [31]. QOL currently is included as an outcome measure in a large percentage of empirical studies on the medical management of ESRD (see Spiegel et al., for a systematic review of biomarkers and health-related QOL in ESRD [32]). Increasingly, QOL in caregivers of ESRD-patients is a topic of research (e.g., [33]), illustrating the growing importance of including the social system of the ESRD-patient in behavioural research.

Patient education is the fourth topic in biopsychosocial research in ESRD-patients. One of the first studies examined the effects of a patient education intervention on adherence to medical regimens in ambulatory haemodialysis patients, using the Health Belief Model [34]. A recent review of intervention studies of this subject concluded that patient education interventions that address self-monitoring of adherence to fluid restrictions seem a promising strategy for ESRD-patients. However, the authors are quite critical of the scientific and clinical value of the reviewed studies [35]. This is in line with current status of patient education research: it is generally agreed that it is not enough to 'educate' patients; they must be partners in disease-management (see Fig. 1 and text below). Merely trying to increase the level of knowledge of patients is inadequate in changing health behaviour and illness behaviour.

The fifth approach takes this point into account. In coping with ESRD, the patient takes on board the personal meaning of the disease and its treatment in his or her attempts to manage associated adaptive tasks. A large study of some 2600 patients on haemodialysis found that patients used different coping strategies for different types of illness-related stressors. Emotion-oriented coping, avoidance and isolated thoughts were the most commonly used coping strategies [36]. Taking this one step further, the Common-Sense Model (CSM) posits how coping is determined by the way patients make sense, cognitively and emotionally, of a health threat. Illness perceptions encompass this 'making sense' of an illness, and they have been assessed with various instruments (questionnaires and drawings) in ESRD-patients. Illness perceptions determine QOL, even controlling for a wide range of clinical and sociodemographic variables [20]. The first intervention study using this approach produced promising results: Karamanidou et al. addressed treatment perceptions, and improved patients' understanding and perceived efficacy of phosphate-binding medications (see below) [37].

The sixth approach involves self-management of a chronic illness and its associated treatment. Self-management is defined as "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition ... to monitor one's condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life" [38, p. 178]. A systematic review of self-management interventions, focusing on fluid-intake restrictions in patients on haemodialysis, finds "some success in decreasing interdialytic weight gain" [39, p. 15], although the authors feel that additional studies with stronger designs and other methodological improvements are needed to explore this area further.

The seventh and most recent approach pertains to diseasemanagement, defined as "an approach to patient care that emphasizes coordinated, comprehensive care along the continuum of disease and across health care delivery systems" [40]. Diseasemanagement has three key features: it uses empowerment strategies (patient-oriented) and decision support tools (professional-directed), preferably supported by changes in the organizational system [41,42]. Christensen and colleagues show how a behavioural self-regulation intervention produced improvements in patient adherence in haemodialysis [43]. Engaging patients to become active participants in their medical and psychosocial care improved their quality of life and additional outcome measures. Bodenheimer and colleagues illustrated the implications of disease-management vs. traditional medical care in relation to 'adherence', where they contrasted 'compliance with the behaviour changes taught to the patient to improve clinical outcomes' with 'increased self-efficacy to improve clinical outcome' [44, p. 2471].

While these seven approaches have been discussed separately in this paper, they do overlap and some approaches use elements from others. Nevertheless, Fig. 1 illustrates the increasing emphasis over time on behavioural research, behavioural outcomes, and the increased participation of ESRD-patients in their own care.

3.2. Systematic literature search

We now turn to the next element in our attempt to build a framework for a behavioural research and care agenda in patients with ESRD: a literature review over the past 8 years. The literature search strategy produced 136 papers. The topics covered by those papers are summarized in Table 1.

Table 1Topics of empirical papers, published in English, in 2000 or later.

Adaptation, coping, depression	24
Care givers	10
Compliance	13
Counseling, education	16
Exercise	21
Psychological aspects, interventions (includes quality of life)	28
Self-management	7
Spirituality	6
Support, family	11

In descending order, the top-five topics were 'psychological aspects and interventions', 'adaptation, coping, depression', 'exercise', 'counseling and education', and 'compliance'. Papers representative of each of these topics are described below.

The topic 'psychological aspects and interventions', includes prospective research into how patient personality is associated with mortality in patients with chronic renal insufficiency [45]. Similarly, Timmers et al. [3] present evidence on how illness perceptions in ESRD-patients are associated with quality of life.

The topic 'adaptation, coping and depression' is illustrated in a study by McDade-Montez et al. [46], who report on symptoms of depression in ESRD-patients on haemodialysis as a unique and significant predictive risk factor for the subsequent decision by patients to withdraw from haemodialysis, with "certain fatal consequences" [47]. Similarly, it includes a paper by Thong et al. [22], who found social support to be an independent predictor of mortality in a prospective study in a large sample of ESRD-patients. This research group recently reported on self-rated health as a predictor of mortality in this sample [23].

An example under the category of 'exercise' is a randomized controlled trial by Castaneda et al. [47]. The authors found that resistance training in patients with chronic kidney disease, not on dialysis therapy, led to reduced inflammation and improved nutritional status in patients who adhered to the training. Exercise training in ESRD-patients focuses on biomedical variables up to now and has not yet been put into an explicit behavioural perspective.

'Counseling and education', in the context of self-regulation theory, was examined by Karamanidou et al. [37]. The investigators aimed to improve patients' adherence to phosphate-binding medication by targeting patients understanding of the function of the medication. The patients were shown a glass model of a stomach, in which the fluid was shown to become more solid after the medication was added. "I see now . . . it has become solid!, so that's what they mean by binding" was one patient's response (p. 211).

The following paper illustrates research falling into the 'Compliance' topic. A randomized controlled trial compared cognitive behavioural group therapy to a wait-list control group in haemodialysis patients [48]. Compliance to haemodialysis fluid restrictions measured by interdialytic weight gain was the major dependent variable. The 4-week intervention comprised of weekly 1-h group sessions that focused on encouraging patients to identify associations between thoughts, emotions, and behaviours. The intervention was found to be feasible and effective [49].

3.3. Screening of related literature

This strategy lead to the identification of research topics that in our view are promising, given research on these topics in other categories of patients with chronic somatic disorders. Table 2 summarizes the results of this strategy. The first is a theoretical orientation: the Self Regulation Theory or the Common-Sense Model (CSM [50]), which offers many opportunities to assess and intervene in psychological concepts that determine various aspects

Table 2A proposed research agenda for behavioural research on patients with ESRD.

1. Common-Sense Model of illness: illness perceptions; treatment perceptions
2. Sexuality
3. Suicide
4. Qualitative methods
5. Family support
6. Self-management interventions

of outcome. For example, in a study by Petrie et al. [51], patients who had suffered acute myocardial infarction participated in a concise intervention programme that focused on adjusting unhelpful cognitions. The positive effects of the intervention were shown as increased participation in cardiac rehabilitation programmes and earlier work resumption. For ESRD-patients, important elements of this theoretical model are the cognitive representation of ESRD, illness beliefs and treatment beliefs, which have been found to be associated with various patient outcomes [3]. These illness perceptions shape self-management behaviour—a crucial element in the theory, which translates into outcomes such as adherence, quality of life, and mortality [24].

Secondly, this review found that other, relatively 'smaller' topics, such as sexuality or suicide are studied, but only to a modest degree [52,53].

In terms of methodology, there is increasing use of qualitative methods in studies with patients who have chronic physical illness, in particular Interpretative Phenomenological Analysis (IPA) [54]. Rather than using questionnaires, qualitative data and/or unobtrusive methods of data collection have been found to be at least as useful as the usual quantitative methods and techniques. Dekkers et al. [55] used IPA to listen to what patients reported when they were invited to tell the story of their renal illness. Hagren et al. [56] used interviews where content analysis identified how "caregivers were not always aware of the existential struggle of patients ... inducing a sense of emotional distance and a sense of vulnerability in the patients" (pp. 294–295).

The topics of 'support, family' and 'self-management' are underresearched in behavioural research with patients who have ESRD. In addition, the empirical evidence for the positive effects of self-management on various outcomes in other chronic illness is quite strong, which gives reason to believe that self-management interventions in ESRD-patients may also be beneficial [57].

4. Discussion

This literature review on recent behavioural research with patients who have ESRD has highlighted a number of issues. The description of seven stages in psychosocial research in ESRDpatients illustrates how patients' involvement in their medical care has increased over the decades, and how self-management has become part and parcel of that care. The literature search revealed that a substantial number of recent empirical papers on ESRD and behavioural topics are available, with 'psychological aspects and intervention' leading the list of publications, followed by 'adaptation, coping, and depression', 'exercise', 'counseling and education', and 'compliance'. However, 'family support' and 'self-management' are under-researched. The Common-Sense Model seems a promising model to inform future research into self-management behaviours in ESRDpatients. Further use of qualitative methods may reveal important psychological issues in ESRD that have not yet been explored in previous research.

A recent paper reviewed psychosocial aspects of ESRD [5]. The authors conclude, just as we do, that "psychosocial issues are understudied yet important in the overall health" (p. 3042). They

identify topics such psychopathology, depression, compliance, anxiety, withdrawal from dialysis, social support, marital and familial aspects, and socioeconomic and cultural subjects as important in this patient category. In our paper, we have attempted to come to an empirical basis for our research recommendations, with an explicit focus on empirical and theoretical bases in psychology as applied to medicine. Compared to the important Cukor et al. [5] paper, we suggest topics such as illness perceptions, sexuality and self-management as worthy fields for future research: we do not emphasize psychopathology, depression and anxiety as such, in order to adhere to an explicit focus on psychology as applied to medicine [58]. The guidelines by the National Kidney Foundation contain similar suggestions (www.kidney.org). The implications for health care professionals and the health care system of a more patient-oriented, comprehensive care system are discussed in an important paper by Levin and Stevens [59]: shared models of care delivery, educational initiatives, and collaborative management are components of this emphasis.

The relatively idiosyncratic selection of topics in the third search strategy may constitute a bias, in that the theoretical basis of much of our research is based in the context of the Common-Sense Model. However, the suggestions in our research agenda are relatively new to ESRD and may, therefore, add new avenues to future research. We acknowledge some limitations in our reviews and suggestions. The topic of 'kidney transplant' was excluded from our analyses: this topic deserves a separate paper. We limited ourselves to papers published in English, which implies we may have overlooked important publications in other languages. Our views on future research topics may reflect a certain bias. We hope this agenda will stimulate discussion within the scientific community of these and other research topics.

Earlier reviews of psychological research in ESRD found that topics centered on compliance and depression in particular [4]. Our review has shown that recent research has added illness beliefs, treatment beliefs, and—to a certain degree—self-management as emerging topics for research and clinical applications. This development supports the move away from patriarchal and paternalistic approaches to 'adherence' towards the empowerment of patients and shared decision-making (cf. [44]).

5. Practice implications

Future research implications from this review involve greater examination of more modern concepts, e.g., illness perceptions, treatment beliefs, self-management, sexuality, and family support. Researchers need to agree on a set of methods, with which to assess 'standard' concepts (i.e., illness beliefs, treatment beliefs, self-management behaviours, depression, and quality of life) so that research can be reliable and comparable across settings. Combining qualitative with quantitative methods ('mixed methods') would enrich the clinical relevance of research questions and research findings. Applying the Delphi method to survey expert opinion may be useful in future work.

It is important that behavioural scientists involve patients and partners, physicians and the public in shaping the research agenda, so that all perspectives can be taken into account. Involving these key parties in also defining a clinical care agenda may be a wise policy, for governments, ESRD-patient organizations, and for behavioural scientists in their quest for evidence-based behavioural medicine and patient education.

Acknowledgement

We thank a reviewer of this manuscript, whose constructive comments helped to strengthen the paper.

Appendix A. Behavioural medicine and renal dialysis studies

A.1. Medline search strategy

- 1. exp Kidney Failure, Chronic/
- 2. end stage renal.tw.
- 3. esrd.tw.
- 4. kidney failure.tw.
- 5. exp Renal Dialysis/
- 6. dialysis.tw.
- 7. or/1-6
- 8. exp psychology/
- 9. psycholog\$.tw.
- 10. exp Behavioral Medicine/
- 11. (health adj2 psycholog\$).mp.
- 12. (behavio\$ adj (health or medicine or therap\$)).mp.
- 13. exp Health Behavior/
- 14. exp Behavior Therapy/
- 15. exp Aversive Therapy/
- 16. avers\$ therap\$.mp.
- 17. exp cognitive therapy/
- 18. (cognitive adj2 therap\$).tw.
- 19. cbt.tw.
- 20. psychotherapy/
- 21. psychotherap\$.tw.
- 22. Autogenic Training/
- 23. (autogenic adj2 training).tw.
- 24. bibliotherapy/
- 25. bibliotherap\$.tw.
- 26. gestalt therapy/
- 27. (gestalt adj3 (therap\$ or psychotherap\$)).tw.
- 28. exp "Imagery (Psychotherapy)"/
- 29. guided imagery.tw.
- 30. nondirective therapy/
- 31. ((client-cent\$ or client cent\$) adj therap\$).tw.
- 32. rogerian therap\$.tw.
- 33. exp Psychotherapy, Brief/
- 34. exp Psychotherapy, Multiple/
- 35. exp psychotherapy, rational-emotive/
- 36. exp Reality Therapy/
- 37. (reality adj orientat\$).tw.
- 38. (reality adj2 therap\$).tw.
- 39. exp Socioenvironmental Therapy/
- 40. ((individual or group or couple\$ or family or marital or marriage or situation\$ or milieu) adj (therap\$ or counsel)).tw.
- 41. sensitivity training.tw.
- 42. role play\$.tw.
- 43. exp counseling/
- 44. counsel\$.tw.
- 45. exp hotlines/
- 46. exp telephone/and exp counseling/
- 47. (hotline\$ or helpline\$).tw.
- 48. ((telephone or phone) adj counsel\$).tw.
- 49. exp Desensitization, Psychologic/
- 50. ((systematic or psycholog\$) adj desensiti\$).tw.
- 51. exp "Mind-Body and Relaxation Techniques"/
- 52. (breath\$ adj (technique\$ or exercise\$)).tw.
- 53. (hypnosis or hypnoti\$).tw.
- 54. hypnotherap\$.tw.
- 55. autosuggest\$.tw.
- 56. ((laugh\$ or hum?r\$) adj therap\$).tw.
- 57. meditat\$.tw.
- 58. ((mind or mental) adj heal\$).tw.
- (relaxation adj (therap\$ or technique\$ or training or exercise\$)).tw.

- 60. exp Implosive Therapy/
- 61. ((implosive or flooding) adj therap\$).tw.
- 62. yoga.tw.
- 63. (tai ji or tai chi).tw.
- 64. exp Anger/
- 65. ((anger or angry) adj3 (control\$ or manage\$ or treat\$ or therap\$ or intervention\$)).tw.
- 66. exp ASSERTIVENESS/
- 67. (assertive\$ adj (skill\$ or training)).tw.
- 68. exp "Habituation (Psychophysiology)",
- 69. (dehabituat\$ or de habituat\$ or habits retrain\$ of habit\$ re train\$).tw.
- 70. exp Problem Solving/
- 71. problem solving.tw.
- 72. exp Adaptation, Psychological/
- 73. coping.tw.
- 74. adaptive behavio?r\$.tw.
- 75. (psychological adj (adjust\$ or adapt\$)).tw.
- 76. psychological debrief\$.tw.
- 77. exp Psychosomatic Medicine/
- 78. (psychosomatic adj (medicine or therap\$ or intervention\$)).tw.
- 79. exp SOCIALIZATION/
- 80. (socializ\$ or socialis\$).tw.
- 81. social skill\$.tw.
- 82. exp Social Support/
- 83. exp caregivers/
- 84. ((social or famils or partners or spouss or parents or friends or neighbo?rs or caregivers) adj support).tw.
- 85. positive behavio?r\$ support.tw.
- 86. biopsychosocial.tw. and (rh.fs. or exp rehabilitation/)
- 87. exp attitude to health/
- 88. ((health or illness\$ or disease\$) adj2 (perception\$ or attitude\$)).tw.
- 89. or/8-88
- 90. controlled.ab.
- 91. design.ab.
- 92. evidence.ab.
- 93. extraction.ab.
- 94. randomized controlled trials/
- 95. meta-analysis.pt.
- 96. review.pt.
- 97. sources.ab.
- 98. studies.ab.
- 99. or/90-98
- 100. letter.pt.
- 101. comment.pt.
- 102. editorial.pt.
- 103. or/100-102
- 104. 99 not 103
- 105. and/7,89,104
- 106. limit 105 to (humans and english language and year = "2000–2007")

References

- [1] Billington E, Simpson J, Unwin J, Bray D, Giles D. Does hope predict adjustment to end-stage renal failure and consequent dialysis? Br J Health Psychol 2008;13:683–99.
- [2] Christensen AJ, Raichle K. End-stage renal disease. In: Christensen AJ, Antoni MH, editors. Chronic physical disorders—behavioral medicine's perspective. Oxford: Blackwell Publishers; 2002. p. 220–43.
- [3] Timmers L, Thong MSY, Dekker FW, Boeschoten EW, Heijmans M, Rijken M, et al. Illness perceptions in dialysis patients and their association with quality of life. Psychol Health 2008;23:679–90.
- [4] Christensen AJ, Ehlers SL. Psychological factors in end-stage renal disease: an emerging context for behavioral medicine research. J Consult Clin Psychol 2002;70:712–24.

- [5] Cukor D, Cohen SD, Peterson RA, Kimmel PL. Psychosocial aspects of chronic disease: ESRD as a paradigmatic illness. J Am Soc Nephrol 2007;18:3042–55.
- [6] Rabindranath KS, Butler JA, Macleod AM, Roderick P, Wallace SA, Daly C. Physical measures for treating depression in dialysis patients. Cochrane Database Syst Rev 2005;CD004541.
- [7] Rabindranath KS, Daly C, Butler JA, Roderick PJ, Wallace S, Macleod AM. Psychosocial interventions for depression in dialysis patients.. Cochrane Database Syst Rev 2005. CD004542.
- [8] Caron-Flinterman JF, Broerse JE, Teerling J, Bunders JF. Patients' priorities concerning health research: the case of asthma and COPD research in the Netherlands. Health Expect 2005;8:253–63.
- [9] Falzon L, Trudeau KJ. Developing a database of behavioural medicine interventions. Health Info Libr J 2007;24:257–66.
- [10] Rundle K, Keegan O, McGee HM. Patients' experiences of dialysis services: are national health strategy targets being met? Iran J Med Sci 2004;173:78–81.
- [11] Mendelssohn DC, Toffelmire EB, Levin A. Attitudes of Canadian nephrologists toward multidisciplinary team-based CKD clinic care. Am J Kidney Dis 2006;47:277–84.
- [12] Regier DA. Somatic presentations of mental disorders: refining the research agenda for DSM-V. Psychosom Med 2007;69:827–8.
- [13] Fisher EB, Thorpe CT, McEvoy DeVellis B, DeVellis RF. Healthy coping, negative emotions, and diabetes management—a systematic review and appraisal. Diab Educ 2007;33:1080–103.
- [14] Sajjad I, Baines LS, Salifu M, Jindal RM. The dynamics of recipient-donor relationships in living kidney transplantation. Am J Kidney Dis 2007;50: 834-54
- [15] Christensen AJ, Antoni MH, editors. Chronic physical disorders—behavioral medicine's perspective. Oxford: Blackwell Publishers; 2002.
- [16] French D, Vedhara K, Kaptein AA, Weinman J, editors. Health psychology. 2nd ed. Oxford: WileyBlackwell; 2010.
- [17] Moher D, Cook DJ, Eastwood S, Olkin I, Rennie D, et al. Improving the quality of reports of meta-analyses of randomized controlled trials: the QUOROM statement. Quality of reporting of meta-analyses. Lancet 1999;354:1896–900.
- [18] Liberati A, Altman DG, Tetzlaff J, Mulrow C, Gøtzsche PC, Ioannidis JPA, et al. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. Ann Intern Med 2009;151:W65-94.
- [19] Jofré R, López-Gómez JM, Moreno F, Sanz-Guajardo D, Valderrábano F. Changes in quality of life after renal transplantation. Am J Kidney Dis 1998;32:93–100.
- [20] Korevaar JC, Boeschoten EW, Dekker FW, Krediet RT, NECOSAD Study Group. What have we learned from NECOSAD? Practical implications for peritoneal dialysis patients. Perit Dial Int 2007;27:11–5.
- [21] Thong MSY, van Dijk S, Noordzij M, Boeschoten EW, Krediet RT, Dekker FW, et al. Symptom clusters in incident dialysis patients: associations with clinical variables and quality of life. Nephrol Dial Transplant 2009;24:225–30.
- [22] Thong MSY, Kaptein AA, Krediet RT, Boeschoten EW, Dekker FW, for the Netherlands Cooperative Study on the Adequacy of Dialysis (NECOSAD) Study Group. Social support predicts survival in dialysis patients. Nephrol Dial Transplant 2007;22:845–50.
- [23] Thong MSY, Kaptein AA, Benyamini Y, Krediet RT, Boeschoten EW, Dekker FW. Association between a self-rated health question and mortality in young and old dialysis patients: a cohort study. Am J Kidney Dis 2008;52:111–7.
- [24] van Dijk S, Scharloo M, Kaptein AA, Thong MSY, Boeschoten EW, Grootendorst DC, et al. Patients' representations of their end-stage renal disease: relation with mortality. Nephrol Dial Transplant 2009;24:3183–5.
- [25] Thong MSY, Kaptein AA. Quality of life in peritoneal dialysis patients. In: Krediet RT, Khana R, editors. Textbook of peritoneal dialysis. 2nd ed., New York: Springer; 2009. p. 523–41.
- [26] Abram HS. Psychiatric reflections on adaptation to repetitive dialysis. Kidney Int 1974;6:67–72.
- [27] Levy NB. What is psychonephrology? J Nephrol 2008;21:S51-3.
- [28] Drayer RA, Piraino B, Reynolds CF, Houck PR, Mazumdar S, Bernardini J, et al. Characteristics of depression in hemodialysis patients: symptoms, quality of life and mortality risk. Gen Hosp Psychiatry 2006;28:306–12.
- [29] Davis B, Krug D, Dean RS, Hong BA. MMPI differences for renal, psychiatric, and general medical patients. J Clin Psychol 1990;46:178–84.
- [30] Oaksford K, Oaksford M, Ashraf M, Fitzgibbon G. Comparing neuropsychological function before and during haemodialysis: a habituating selective deficit for prose recall. Br J Health Psychol 2008;13:273–89.
- [31] Elkington JR. Medicine and the quality of life. Ann Intern Med 1966;64:711-4.
- [32] Spiegel BM, Melmed G, Robbins S, Esrailian E. Biomarkers and health-related quality of life in end-stage renal disease: a systematic review. Clin J Am Soc Nephrol 2008;3:1759–68.
- [33] Belasco A, Barbosa D, Bettencourt AR, Diccine S, Sesso R. Quality of life of family caregivers of elderly patients on haemodialysis and peritoneal dialysis. Am J Kidney Dis 2006;48:955–63.
- [34] Cummings KM, Becker MH, Kirscht JP, Levin NW. Intervention strategies to improve compliance with medical regimens by ambulatory haemodialysis patients. J Behav Med 1981;4:111–27.
- [35] Welch JL, Thomas-Hawkins C. Psycho-educational strategies to promote fluid adherence in adult haemodialysis patients: a review of intervention studies. Int J Nurs Stud 2005;42:597–608.
- [36] Yeh SC, Chou HC. Coping strategies and stressors in patients with haemodialysis. Psychosom Med 2007;69:182–90.
- [37] Karamanidou C, Weinman J, Horne R. Improving haemodialysis patients' understanding of phosphate-binding medication: a pilot study of a psycho-

- educational intervention designed to change patients' perceptions of the problem and treatment. Br | Health Psychol 2008;13:205–14.
- [38] Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. Patient Educ Couns 2002;48:177–87.
- [39] Sharp J, Wild MR, Gurnley Al. A systematic review of psychological interventions for the treatment of nonadherence to fluid-intake restrictions in people receiving haemodialysis. Am J Kidney Dis 2005;45:15–27.
- [40] Ellrodt C, Cook D, Lee J, Cho M, Hunt D, Weingarten S. Evidence-based disease management. J Amer Med Assoc 1997;278:1687–92.
- [41] Lemmens KM, Nieboer AP, van Schayck CP, Asin JD, Huijsman R. A model to evaluate quality and effectiveness of disease management. Qual Saf Health Care 2008;17:447–53.
- [42] Chiaramonte D. Who's afraid of the empowered patient? J Amer Med Assoc 2008;300:1393-4.
- [43] Christensen AJ, Moran PJ, Wiebe JS, Ehlers SL, Lawton WJ. Effect of a behavioral self-regulation intervention on patient adherence in hemodialysis. Health Psychol 2002:21:393–7.
- [44] Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. J Amer Med Assoc 2002;288:2469–75.
- [45] Christensen AJ, Ehlers SL, Wiebe JS, Moran PJ, Raichle K, Ferneyhough K, et al. Patient personality and mortality: a 4-year prospective examination of chronic renal insufficiency. Health Psychol 2002;21:315–20.
- [46] McDade-Montez EA, Christensen AJ, Cvengros JA, Lawton WJ. The role of depression symptoms in dialysis withdrawal. Health Psychol 2006;25:198–204.
- [47] Castaneda C, Gordon PL, Parker RC, Uhlin KL, Roubenoff R, Levey AS. Resistance training to reduce the malnutrition-inflammation complex syndrome of chronic kidney disease. Am J Kidney Dis 2004;43:607–16.
- [48] Sharp J, Wild MR, Gumley AI, Deighan CJ. A cognitive behavioral group approach to enhance adherence to haemodialysis fluid restrictions: a randomized controlled trial. Am J Kidney Dis 2005;45:1046–57.

- [49] Davidson KW, Trudeau KJ, Ockene JK, Orleans CT, Kaplan RM. A primer on current evidence-based review systems and their implications for behavioral medicine. Ann Behav Med 2004;28:226–38.
- [50] Leventhal H, Brissette I, Leventhal EA. The common-sense model of self-regulation of health and illness. In: Cameron LD, Leventhal H, editors. The self-regulation of health and illness. London: Routledge; 2003. p. 42–65
- [51] Petrie KJ, Cameron LD, Ellis CJ, Buick D, Weinman J. Changing illness perceptions after myocardial infarction: an early intervention randomized controlled trial. Psychosom Med 2002;64:580–6.
- [52] Coelho-Marques FZ, Wagner MB, Poli de Figueiredo CE, d'Avila DO. Quality of life and sexuality in chronic dialysis female patients. Int J Impot Res 2006;18:539–43.
- [53] Kurella M, Kimmel PL, Young BS, Chertow GM. Suicide in the United States end-stage renal disease program. J Am Soc Nephrol 2005;16:774–81.
- [54] Smith J, Jarman M, Osborn M. Doing Interpretative Phenomenological Analysis. In: Murray M, Chamberlain K, editors. Qualitative health psychology. London: Sage; 1999. p. 218–40.
- [55] Dekkers W, Uerz I, Wils JP. Living well with end stage renal disease: patients' narratives interpreted from a virtue perspective. Ethic Theor Moral Pract 2005;8:485–506.
- [56] Hagren B, Petersen IM, Severinsson E, Lützén K, Clyne N. Maintenance haemodialysis: patients' experiences of their life situation. J Clin Nurs 2005;14: 204, 300
- [57] Newman S, Steed L, Mulligan K. Self-management interventions for chronic illness. Lancet 2004;364:1523–37.
- [58] Kaplan R, Spring B, Davidson K. EBMH Notebook: APA, NAMI, NMHA, and evidence-based behavioral medicine: a comment. EBMH 2006;9:32–4.
- [59] Levin A, Stevens LA. Executing change in the management of chronic kidney disease: perspectives on guidelines and practice. Med Clin North Am 2005;89:701–9.