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# **To dialyse or not to dialyse - is that the question? A psycho-social perspective on dilemmas concerning dialysis in people with dementia**

## **Abstract**

There is increasing recognition that the organisation of healthcare into specialist areas of practice can be counterproductive for older people with multiple morbidities and that dementia can raise particular challenges in healthcare. In the context of treatment for chronic kidney disease these challenges concern complex decisions about the suitability and efficacy of dialysis and other treatments. This article draws on a literature review to present a psycho-social perspective on these decisions. It considers the value of the concept of 'dementia-friendliness' for nephrology practice, and suggests how this could provide a valuable frame of reference for nephrology professionals to ensure they are best equipped to work with people living with dementia and their carers and to ensure that the individual patient is truly at the centre of their treatment regime.

## **Introduction**

Increased life expectancy in the UK and other Western countries has been associated with an increase in complex long term illness in later life and the provision of health care for older people is taking place within very challenging political, economic and cultural contexts, with implications for practice. Dementia, for example, has been described by the Department of Health in England as 'one of the biggest health challenges ever' (2013:2), not only because of increased demand related to demographic trends but also because of severe and long-lasting constraints on health and social care expenditure. A range of clinical, legal, ethical and social issues arise, therefore, when decisions are made about the efficacy and suitability of treatments and interventions. When individuals have both chronic kidney disease and dementia, the complexity of these issues is highlighted starkly. When an individual with dementia also has end-stage CKD, a range of questions arise about what is the most efficacious and suitable treatment and these are not merely clinical but also legal, ethical and social. This literature review was conducted as a preliminary to a full-scale study – *Dilemmas around dialysis in people with dementia*. The aim of the study is to inform and support the decision-making of clinicians and carers when acting in the best interests of a patient with dementia who lacks capacity and requires treatment for advanced chronic kidney disease (CKD).

This review focuses on the *social* issues that arise in treatment decisions associated with dialysing a person with dementia and the attitudes and perspectives of professionals, patients and family carers involved. It begins with a brief background explanation of the characteristics of dementia and CKD. The process of the review is

then explained and the key findings identified, with a discussion of their significance for future research and practice development.

## Background

The term 'dementia' used in this review refers to a set of symptoms, including memory loss and associated difficulties with thinking, problem solving and language (Alzheimer's Society 2013). People with dementia may experience changes in their mood or behaviour. They may have a greater tendency to become irritable, sad, distressed or angry than was previously the case. Dementia may also give rise to physical changes such as muscle weakness and weight loss, as well as changes in visual perception leading to problems of coordination and sometimes hallucinations. The rate at which such changes take place is highly variable. The prevalence of dementia increases with age: in the UK in 2013, almost 95% of the 815827 people who had dementia were aged over 65, representing 1 in 14 of over 65s in the population (Alzheimer's Society 2014). Alzheimer's disease, vascular dementia and dementia with Lewy bodies, the three most common causes of dementia, give rise to pathological processes that are progressive and irreversible. Clinical interventions, including diagnosis, treatment and management of patients are guided by this medical explanation of dementia (see for example NICE 2015) but there is growing understanding and acceptance – including in the medical literature - of the importance of *social* factors in the course and outcomes of dementia (Fratiglioni, Paillard-Borg and Winblad 2004). The Alzheimer's Society (2015:1) says, '*[h]ow others respond to the person, and how supportive or enabling the person's surroundings are, also greatly affect how well someone can live with dementia*'. Moreover, accounts given by people experiencing mild and moderate dementia reveal the importance of positive support from others to their potential to live well with dementia (Beard, Knauss and Moyer 2009).

CKD is an irreversible and incurable condition that also varies considerably in its severity and rate of progression and which also increases in prevalence with age. It is estimated by the British Kidney Patients' Association (BKPA) that about 50% of people aged over 75 have some degree of CKD (BKPA 2014). In CKD kidneys are damaged, diseased or not functioning properly. Excess fluid, salt and waste products, which would be filtered out by healthy kidneys, are left to build up, causing unpleasant symptoms and damage to other organs. The main method of treating end-stage CKD is haemodialysis, which requires a co-ordinated multi-disciplinary effort from the GP, nephrologist, dialysis nurses or technicians, dietician and social worker, as well as the patient. In haemodialysis a small operation is performed to create a 'fistula', through which blood can flow from the patient through a machine to be filtered. Individuals are connected to a haemodialysis machine, usually 3 times a week for 3 to 5 hours, in some cases at home (BKPA 2013a). An alternative treatment, *peritoneal dialysis*, involves the insertion of a catheter into the abdominal cavity to administer a cleaning liquid, or dialysis solution and the drainage of waste

products from the body. This process ('exchange') takes about 30-40 minutes, in most cases 4 times a day with 4 to 8 hours between exchanges.

*Conservative treatment*, might be chosen in preference to either of these two methods by those who might find them too difficult to manage, too intrusive on their lives or too time consuming. Where individuals have co-morbidities CKD might be considered relatively unimportant and haemodialysis can complicate other treatments. According to the BPKA: '[f]or those who are easily confused, for example people who have dementia, dialysis may seem frightening or upsetting' (BKPA 2013b) and conservative treatment preferred. In a conservative treatment regime, the symptoms of CKD are minimised through adherence to a diet low in salt and other foodstuffs that lead to high levels of excess fluid and waste products in the blood, and drugs are given to reduce unpleasant symptoms. It is not as effective as dialysis and the patient will die more quickly, although it is difficult to say how much more quickly, than if they had dialysis.

## **The literature review process**

A systematic review of the literature was begun, using combinations of the words *dialysis* [and] *dementia* [and] *carers* [and] *social*. This yielded an unmanageable quantity of articles but when two words were combined to form a search term the number of articles was reduced drastically, with few appearing to be relevant to this study, and when more than two words were combined, there were no articles at all. In light of this, an alternative approach was adopted to meet the aims of the study. First, we examined literature on dementia as a psycho-social phenomenon and utilised this perspective to consider the types of issues faced by those living with both dementia and CKD. Selected articles identified through searches<sup>1</sup> of the Sociological Abstracts data base and Google Scholar were used to identify themes associated with psycho-social adaptation and coping in CKD. Additional articles covering this and related topics were identified through 'snowballing' of promising citations. Selected policy literature concerned with 'personalisation' and 'the self' in later life, was identified.

Table 1 sets out the route by which a piece of literature cited came to be included. It can be seen from this that this review is not 'systematic' in the classical sense but is highly organised as well as transparent about its process.

## **Table 1 about here**

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<sup>1</sup> Using combinations of search terms *dialysis* [or] *chronic kidney disease* [or] *end stage renal disease* [and] *dementia* [and] *adaptation* [or] *psycho-social* [or] *social* [or] *carers* [or] *caregiver*.

## **Psycho-social explanations of dementia: the person comes first**

Although its influence remains paramount in the clinical context, the bio-medical explanation of dementia has been subjected to a range of challenges. Kitwood (1997) notably reversed the order of components in the bio-medical explanation by ascribing greater significance to the psycho-social construction and consequences of dementia *over* its organic pathology. Kitwood's stance arose from a moral imperative for all persons to be motivated by and to act out concern for others through respect for their personhood. People living with dementia are the paradigmatic example of those whose claim to personhood may be overlooked by others. Kitwood argued that personhood is carried within the agency, sociability and sentience of all persons through interaction with others and can only be fully comprehended from the perspective of each person's lived experience. Thus, the common perception of dementia as '*the death that leaves the body behind*' and treatment of people with dementia as 'empty shells', deprives them of their essential personhood. Without wholly rejecting the biological basis of dementia, Kitwood asserted that its medicalisation reflects and perpetuates a '*malignant social psychology*', which, he argued, flows from Western cultural values of individualism and '*hypercognitivism*' (see Kitwood 1987, Kitwood 1990, Kitwood and Bredin 1992, Kitwood 1993).

Kitwood and Bredin's (1992) identification of 12 indicators of relative well being linked to 4 '*global sentient states*'<sup>2</sup> has provided a theoretical basis for models of person centred care designed to acknowledge and respond to the full personhood of people living with dementia in everyday interaction with others. One of the best known is dementia care mapping (DCM), which is an observational tool used in dementia care settings to judge activities and interventions that contribute to, or detract from, relative states of well being experienced by people living with dementia during the usual course of each day (Brooker 2005). It is an approach that emphasises the relational nature of care and in recent years has been extended beyond the most direct relationships of care to become a community concern in the form of the Dementia Friends initiative ([www.dementiafriends.org.uk](http://www.dementiafriends.org.uk)). For services to be 'dementia friendly, they would need to ensure not only that people with dementia are not discriminated against within service setting but also that their particular needs as individuals with dementia are understood sufficiently well to ensure their treatment maximises their wellbeing.

## **Dementia friendly' treatment of CKD**

A key question for this review concerns the relevance of this approach to the clinical setting, particularly in the context of CKD and decisions about dialysis. Allon et al (2014: 804) provide an account of a '*demented*' patient who disrupts '*what should be*

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<sup>2</sup> They are: a sense of personal worth; a sense of agency; social confidence; and a sense of hope.

*the calm environment of the dialysis center*' by repeatedly attempting to pull the needle from their arm and displaying agitated behaviours that cause distress to other patients. This difficult situation is compounded by the patient's son, a serving police officer (in the USA), who becomes verbally aggressive to staff who are all the more threatened by the knowledge he is carrying his service firearm. Allon et al note that dialysis facilities throughout the USA have learned to require the families of patients with dementia to provide 'sitters', but that some decline to do so, and in any case, patients sometimes display unsafe behaviours. They ask what should be done to prevent such patients from endangering themselves and others, and from taking up a disproportionate amount of staff time and attention. This account can be analysed in terms of Kitwood's malignant social psychology, since it suggests a culture in which people with dementia are regarded as 'abnormal' because of their inability to conform to the rules observed by 'normal' dialysis patients. It follows that attention to patients with dementia detracts from the 'real' purpose of the centre and its staff, which is to deliver dialysis to those who are willing and able to cooperate. Although this example is set in the USA the underlying dynamics are likely to feature elsewhere, including in the UK.

Situating the dilemmas concerning 'to dialyse or not to dialyse' within the *cultures* of dialysis units and wider nephrology treatment settings prompts a preceding, broader set of questions, requiring serious consideration of dementia as a psycho-social phenomenon located within the interaction between nephrology professionals and their patients with dementia and of the practice environments of nephrology departments. These questions include how nephrology professionals currently conceptualise dementia, what is required to develop more 'dementia friendly' perspectives and practices with individuals, their families and carers. In this particular context we might consider, for example, how practices of '*empowering communication*' might be developed (Adams and Gardiner 2005) and patient choice facilitated (Tyrrell, Genin and Myslinkski 2006) during consultations with patients with mild or moderate dementia and their carers? Another possibility would be the development of a form of DCM for use in dialysis units that takes account of non-verbal expressions of consent or refusal in patients with moderate or severe dementia. An adapted form of DCM might also provide for objective observation of indicators of wellbeing and ill-being in each patient's actual experience of dialysis, and inform wellbeing enhancing adjustments.

A concrete illustration of this suggestion involves the use of time. As already discussed, dialysis involves long periods of time spent attached to medical machinery. A number of researchers have demonstrated that fragmented and personal formulations of time are an important feature of the experience of personhood in later life (Hazan 1994, Baars 2007, Bytheway 2011). An adapted form of DCM could help to tailor the delivery of dialysis by identifying the time slots most tolerable for individual patients based on what has been observed of their personal formulations of time. It might also help to identify activities and interactions

that are most strongly associated with wellbeing in particular individuals and in which they might be engaged during their time attached to the dialysis machine.

Such an approach cannot provide a prescription that resolves the ultimate dilemma of to dialyse or not to dialyse, but it can help to inform and guide those involved in each individual instance of that dilemma. More importantly, an approach to the dilemma that is rooted in dementia friendly practice is one that acknowledges how the culture of nephrology treatment can itself contribute to the dilemma and actively seeks to eradicate barriers and complications caused by practices which treat patients with dementia as 'other' compared with those patients who do not have dementia. It is therefore an approach that brings people with dementia into the mainstream of nephrology practice rather than seeing them as inconvenient imposters into it.

It is important to emphasise that our intention is not to characterise the culture of nephrology treatment as one in which patients' personhood is routinely neglected by an exclusive preoccupation with the function of their kidneys and technical management of their condition. There is a great deal of literature that demonstrates that nephrology professionals are very aware of the importance of supporting the individual personhood of their patients, not least for the positive impacts it can have on their condition and treatment outcomes (see for example Bennett 2011, Yousseff, Harris and O'Donoghue 2015). It is surely also the case that some nephrology professionals and dialysis centres are already engaged in practice that reflects person centred dementia care and there are helpful examples of practice frameworks that draw together knowledge and expertise from a range of disciplines and practices. The argument here is for the possibility that these examples are developed into practice frameworks that set a standard for the care of people with dementia in treatment for CKD. For example, the NHS has developed a framework for end of life care in advanced kidney disease (NHS 2015) yet despite the very high proportion of people with CKD who are aged over 75, this publication contains the word 'dementia' only once. Similarly, qualitative research conducted with GPs suggests that more needs to be done to develop their links with specialist nephrology and other secondary health services to enhance conservative treatment of patients with CKD and dementia (Tonkin-Crine et al 2015). To establish a standard for good practice where people with dementia have end-stage CKD, practice frameworks will inevitably be inter-disciplinary, enabling nephrology professionals and GPs to draw on the knowledge and expertise of colleagues who specialise in dementia care.

### **Psychological coping with CKD and dialysis**

The psychological and emotional challenges faced by people with CKD are examined in a range of studies in which the concept of *coping* is highlighted. De Guzman et al (2009), for example, explored the language used by a small sample of Filipino elders in describing their lived experience of haemodialysis, which revealed

the emotional effort expended in coping with their situation and the cognitive mechanisms they employed in order to give it meaning. The concept of '*coping as scaffolding*' describes clinging to something of importance, such as spiritual belief and significant relationships. '*Coping as sailing*' describes finding a way of moving on, which for some means forgetting about dialysis in between treatments and '*surrendering*' to it only when the next treatment is due. '*Coping as sanguinity*' describes the serenity derived from coping itself, its reward realised in survival and continuity of self and in the facilitation of present and future coping. This study provides an insight into the complexity of adaptation to CKD in later life, and the potential for older people undergoing dialysis to call on their personal, social and cultural capital to maintain a tolerable quality of life despite the emotional and physical challenges of their condition and its treatment. It echoes earlier work by Mok and Tam (2001) among a sample of patients in Hong Kong.

In a similar vein, Yeh and Chou (2007) explored the coping strategies of 50 Taiwanese patients undergoing haemodialysis and found that '*emotion-focussed coping*' was more frequently deployed over '*problem-solving coping*'. In other words, rather than addressing stressful elements of their situation by attempting to manage or change them through actions directed externally, participants typically sought to understand problems as arising from circumstances beyond their control and to ameliorate negative emotions associated with them.

Taken together, these studies call attention to the considerable effort of psychological adaptation required to maintain a degree of hope and resilience through CKD and dialysis, a task made more difficult in the context of dementia, particularly where cognitive impairment complicates and obscures psychological coping mechanisms or causes difficulty in language skills. Therefore, an important aspect of responding to treatment dilemmas in CKD with dementia would involve nephrology professionals (and others) genuinely striving to understand how their patient experiences and ascribes *meaning* to their condition and the treatment they are receiving for it. Specialist psychology is already a well established feature of nephrology services and arguably its remit could be extended to better understand the complex interaction between CKD and dementia.

A number of authors, including Kitwood (1997), place considerable emphasis on the importance of awareness of personal biography in promoting personhood in the context of dementia. Reminiscence therapy and similar activities such as life story work (McKeown et al 2010, Cheston 1996) are now frequently used as techniques within person centred practice. Another important point of access to personal biography is via those, such as families and friends, who have their own firsthand knowledge of the patients' personal history, having shared in it in some way. Befriending schemes, which have also been shown to improve wellbeing in those with mild and moderate dementia, (Mulvihill 2011), could play a part in helping professionals to understand an individual's personal biography. It follows that the

active involvement of patients' relatives in the planning and delivery of treatment for CKD for people with dementia has potential for development so as to maximise their ability to cope (Atchley 1991, Coleman, Ivani-Chalian and Robinson 1998, Edvardsson, Fethersonhaugh and Nay 2010).

### **Caring for carers**

Adams (2001) suggests that Kitwood's legacy of person centred care has taken insufficient account of those who care for them, particularly unpaid carers. At the same time, over-reliance on unpaid carers is frequently identified as the essential resource that enables a person with dementia to maintain independent living (Seddon and Robinson 2001, Knapp et al 2007). Heavy reliance on unpaid carers is similarly a feature of treatment for CKD in general and of dialysis in particular. A key factor in decisions about dialysis is likely to be the social support network available to the patient and more particularly the presence of family or other unpaid carers living with or close to the patient. In a comparative study of French octogenarians receiving treatment for CKD, Joly et al (2003) found that '*social isolation*' defined simply as '*living alone*' was strongly associated with the decision to offer conservative treatment rather than dialysis. Similarly, a large proportion of potential participants excluded from an Australian study into reasons for stopping or not starting dialysis were cognitively impaired patients who did not appear to have a carer (Ashby et al 2005). Already discussed above, Allon et al (2014) describe the situation in the US where dialysis centres have come to require family carers to attend as '*sitters*' during dialysis sessions for relatives with dementia in order to minimise any potential disruption and hazards to the patient and others.

A systematic review of support services available to non-professional caregivers of people with CKD by Tong, Sainsbury and Craig (2008) concludes that a growing number of people with CKD rely on non-professional caregivers and that such caregivers are often neglected or under-prioritised. Other studies (Allen Furr 1998, White and Grenyer 1999, Belasco and Sesso 2002, Belasco et al 2006, Xiao-Qing et al 2008, Zeigert, Fridland and Lidell 2009 and Ekelund and Andersson 2010) also identify the importance of support to caregivers of people undergoing treatment for CKD and the impact of the caring role on caregivers. Evidence on the efficacy of specific interventions to support caregivers is lacking but the studies cited above collectively point to areas in which support for carers is required. These include coming to terms with the psychological impacts of their situation, dealing with the emotional aspects of dependency and feelings associated with a sense of loss. Another area involves the knowledge and skills required to be an effective carer for someone with CKD, a principal consideration being condition-specific information and guidance in the management of diet. Finally, support is required to address disruption caused to 'normal' life. Time spent travelling to and from hospital and sitting with patients undergoing dialysis are key practical considerations; the actual and opportunity costs (e.g. through the loss of paid employment) being very significant factors. These are important factors for professionals too, particularly in

relation to offering dialysis over conservative treatments. The lack of evidence as to the effectiveness of particular psycho-social support interventions in CKD may, in part at least, reflect the particularity of each case, which would support the approach of treatment tailored to individual circumstances

### **Choice, control and co-production**

An additional related theme in the literature concerns the extent to which individuals are able to exercise choice and control over treatment decisions. Mol (2008) investigated patient choice in the context of diabetes treatment in the Netherlands and concluded that positive treatment outcomes were achieved through attention to the complex psycho-social circumstances intertwined with diabetes and (often) other complicating conditions. Mol observed that the most effective strategies were 'co-produced' by clinicians working with the patient and their family or unpaid carers to accommodate achievable treatments within the real constraints of individual lifestyles. This involved constant adjustment or '*doctoring*' of the treatment regime to achieve the best possible compromise between optimal treatment and outcomes, and that which the patient actually values and can achieve in practice. Clinicians adapted their advice and interventions to suit the particular capabilities and motivations of each patient and demonstrated understanding rather than judgement of non-compliance so that set-backs were overcome and the therapeutic relationship was preserved for the longer term. These findings reflect a wider literature promoting co-production and personalisation as a feature of health and social care policy in the UK (see Hunter and Ritchie 2009, Loeffler et al 2011).

Applied to those living with CKD and dementia the idea of co-production provides a means for nephrology professionals to work positively with patients whose psychological coping strategies and resources may not be conducive with optimal treatment of their condition. The principal concern is not the likely effectiveness of one treatment over another, but conscious respect for individual personhood and wellbeing as the key factor of all treatment decisions. To an extent, the term 'co-production' describes practices that have a long history of 'shared decision making' (see for example Makoul and Clayman 2006). Essentially, it requires a commitment to create solutions that are led by the individual's understanding of their social and psychological circumstances and the preferences that flow from this. This calls for doctors and other professionals to place their expert knowledge and skills at the disposal of each individual, but to hold back from prescribing what they consider to be the most appropriate form of treatment in favour of considerations of what the individual is able and willing to cope with. The co-production model provides a vehicle for relatives and carers to become positively involved in treatment decisions, not by calling on them to make one off 'best interests' decisions, but by involving them on an on-going basis as 'people who know and like the person' and are concerned with the continuity of their personhood (Hunter and Ritchie 2009).

### **Conclusion**

The task of this review was to consider dilemmas around dialysis in people with dementia from a social perspective. It was hoped that literature would be identified that might guide nephrology professionals in resolving the dilemma of to dialyse or not to dialyse patients who present with dementia, particularly those with moderate or severe dementia. Without neglecting such aspirations completely, the review has taken a more circuitous route to arriving at identifying the key themes for a future research agenda.

The 'primary' social issue that has been investigated has been that of dementia as a psycho-social phenomenon. Person centre dementia care offers a positive response to the needs of people living with dementia but requires different knowledge and skills and a new frame of reference for those in contact with people with dementia. Thus, the principal dilemma is not the question of whether or not dialysis is an appropriate treatment in a particular case, but how can nephrology treatment become more dementia friendly so that the individual patient is truly at the centre of their treatment regime whatever it entails. This calls for a better understanding of how nephrology professionals can be best equipped to work with people living with dementia and their carers and of the potential for the development of dementia friendly culture and practices.

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**Table 1: Literature – route for inclusion**

Route for inclusion		Citations
1	Kitwood and associated literature (known to authors)	Adams 2001. Adams and Gardiner 2005. Beard, Knauss and Moyer 2009. Brooker 2005. Dewing 2008. Fratagioni, Paillard-Borg and Winblad 2004. Kitwood 1987, 1990, 1993, 1997. Kitwood and Bredin 1992. Knapp et al 2007. NICE 2015. Packer 2003.
2	Sociological Abstracts (search)	Allon et al 2014. Ashby et al 2005. De Guzman et al 2009. Ekelund and Andersson 2010. Joly et al 2003. Xiao-Qing et al 2008. Ziegert, Fridlund and Lidell 2009.
3	Google Scholar (search)	Allen-Furr 1998. Belasco et al 2006. Cheston 1996. Edvardsson, Fetherstonhaugh and Nay 2010. Mok and Tam 2010. Mulvihill 2011. Naylor et al 2015. Tong, Sainsbury and Craig 2008. White and Greyner 1999. Yeh and Chou 2007. Yousseff, Harris and O'Donoghue 2015. Tonkin-Crine et al 2015.
4	Promising citations 'snowballed' from 2 and 3 above	Belasco and Sesso 2002. Bennett 2001. British Kidney Patient Association 2014 (a, b & c 2013). Forbat 2003. Naylor et al 2013. Seddon and Robinson 2001. Tyrrell, Genin, and Myslinkski 2006. Makoul and Clayman 2006.
5	Personalisation literature / self in later life	Alzheimer's Society 2014. Atchley 1991. Baars 2007. Bytheway 2011. Clarke 2005. Coleman, Ivani-Chalian and Robinson 1998. Fotaki 2006. Glendinning et al 2008. Hazan 1994. Hunter and Ritchie 2007. Loeffler et al 2011. NHS 2015. Mckeown et al 2010. Mol 2008.