

# Health literacy in chronic kidney disease education

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## Abstract

Health literacy is an area of nursing research that is a relatively new concept in the understandings of the patient experience of chronic disease self management. Limited health literacy has been identified as a potential contributor to poor health outcomes including poor CKD outcomes. This paper critiques the link between health literacy and primary health care education with a focus on the issues surrounding people with chronic kidney disease and those who have the additional co-morbid conditions of diabetes mellitus and/or have entered older age. In addition, the paper presents three assessment tools currently being used to measure the health literacy and offers some strategies to increase the health literacy of people with CKD. Finally, suggested areas for future nephrology nursing research in this new area of health literacy are offered.

## Introduction

Health education is an essential competency within the nursing role. However, methods to convey clarity of the information being provided to assist understanding still need to be developed (Mason 2001). The link between the discourse of health literacy and patient education provides a new perspective into measurable primary health care education (Davis & Wolf 2004; Wolf et al. 2005; Nutbeam 2009). The patient-centred health literacy approach (Berkman et al. 2004; Becker 2009) is a key direction for future nephrology nursing research as a growing understanding of the importance of health literacy may be a significant determinant in the successful preservation of kidney health (Devraj & Gordon 2009).

Health literacy as a determinant of chronic disease self-management (Cordasco et al. 2009) has become an important issue in both national policy and research agendas (Schillinger et al. 2002; Protheroe et al. 2009). Recently the Australian Commission on Safety and Quality in

Health care identified health literacy as a strategy to improve the quality of health care in Australia (Adams et al. 2009; Australian Commission on Safety and Quality in Health care 2009). This strategy is timely as a study by Barber et al. (2009) alarmingly suggested that up to a quarter of the Australian population may have limited health literacy. Health literacy research is timely as CKD is a significant contributor to Australia's current health care expenditure at 1.7% of the total national costs with an expected increase over the next ten years (Australian Institute of Health and Welfare 2009). This paper makes a contribution to current nephrology nursing practice by critiquing the issue of health literacy and its relevance to primary health care education. The paper provides an overview of health literacy, the important link between the health literacy of people with Chronic Kidney Disease (CKD) to current nephrology nursing practice and how health literacy has impacted on other populations with chronic disease self management issues such as the older population and those with

## Key Words

Chronic kidney disease, health literacy, nephrology, nursing, research, self care

diabetes mellitus. Current measurement tools and strategies that could be implemented to improve health literacy are explained. Finally, areas for future nephrology nursing research are outlined.

## An Overview of Health Literacy

Health literacy is a complex human competency that evolves over a lifetime (Zarcadoolas, Pleasant & Greer 2005) and involves general literacy skills such as reading fluency as well as incorporating a unique set of decision making skills which includes listening, speaking, writing and numeracy to successfully navigate health care information (Paasche-Orlow et al. 2005; Bennett et al. 2009). Irrespective of educational background, people with acute and chronic health conditions can be challenged when navigating the health care system and understanding information to effectively self manage their own personal health care (Davis et al. 2002; Davis & Wolf 2004; Baker et al. 2007; Cordasco et al. 2009; Sakraida & Robinson 2009). This challenge is particularly relevant in the context of increasing technological advancements such as renal replacement therapies within today's changing health care environment (Baker et al. 1998; Zarcadoolas et al. 2005; Fink 2008).

A proposed definition for health literacy is "the ability to obtain, process and understand health information to make appropriate decisions about one's health and medical care" (Neilsen-Bohlman et al. 2004, p 100).

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Therefore this definition of health literacy refers to the competency of the person to access health care services, understand complex health concepts, participate in a private dialogue about their personal health with their health professional and finally make appropriate decisions about their own health care so as to reduce health risks and increase their quality of life (Nutbeam 1999; Zarcadoolas et al. 2005). Various terms defining suboptimum health literacy have been described in the literature, examples used have been poor, low, inadequate or marginal (Weiss 2005; Tang et al. 2008; Cordasco et al. 2009; Jeppensen, Coyle & Miser 2009). There is still debate on the definitions of each category of suboptimum health literacy in the nursing literature, so to avoid confusion and reduce ambiguity (Speros 2005), the one term “limited” health literacy has been chosen to be used in this article when describing a situation where people have difficulty obtaining, processing or understanding health information.

### **Consequences of Limited Health Literacy**

The consequences of limited health literacy have been found to influence health professional interactions and be a significant risk factor for poor health outcomes (Berkman et al. 2004). Limited health literacy may have an impact on accessing preventative health services, as well as have an effect on understandings of disease and treatment options, uncontrolled chronic disease self management and rising health care costs (Schillinger et al. 2002; Davis & Wolf 2004; Neilsen-Bohlman et al. 2004; Safeer & Keenan 2005; Wolf et al. 2005; Tessler Lindau et al. 2006; Baker et al. 2007). People who have limited health literacy are less likely to understand or participate in primary health care disease prevention and health promotion programs resulting in more frequent hospitalisations (Scott et al. 2002; Davis & Wolf 2004; Baker et al. 2007; Eichler et al. 2009). Similarly, people from ethnic backgrounds who have limited English language comprehension and therefore limited health literacy are more likely to misunderstand medical directions, have a lower level of chronic

disease self management skills, lower levels of treatment compliance, experience worse health outcomes and are at risk of a greater usage of acute health care services (Cordasco et al. 2009). Frankel (2008) found that those whose ability to communicate with health care professionals was limited due to a foreign language, deafness or a mental health issue were least likely to receive adequate health care services. Therefore, the people with the greatest health care needs may be the least able to access and process information and function successfully through the health care system (Tang et al. 2008).

### **Health Literacy and the Older Population**

Limited health literacy is prevalent in the older population (Baker et al. 1998; Schillinger et al. 2002; Gazmararian et al. 2003; Calderón et al. 2008) and it is this population who has the largest burden of chronic diseases including CKD (Davis et al. 2002; Gazmararian et al. 2006; Cordasco et al. 2009). In Cordasco et al. (2009) study, 90% of their subjects had two or more chronic diseases with 42% of their older subjects having four or more chronic diseases. Factors contributing to limited health literacy in this population include declining cognitive function and memory, increased time since formal education and decreased sensory abilities such as impaired vision as a result of chronic and co-morbid conditions (Schillinger et al. 2002; Safeer & Keenan 2005; Gazmararian et al. 2006). Wolf et al. (2005) found that older people with limited health literacy had significantly poorer physical and mental health functioning with higher rates of hypertension, diabetes mellitus, heart failure and arthritis. While a study by Baker et al. (2007) found that mortality from cardiovascular disease was increased in an older population with limited health literacy.

Davis et al. (2002) reported that older people had the greatest burden of cancer and that limited health literacy resulted in a lack of understanding of cancer control, misunderstanding of susceptibility to cancer and the benefits of early screening recommendations. This finding was

confirmed by von Wagner et al. (2009) who found that limited health literacy in older people influenced information seeking and was associated with a lack of confidence to participate in bowel cancer screening.

### **Limited Health Literacy and the CKD Population**

The linking of limited health literacy to a lack of knowledge of preventative health behaviours is a significant issue for people with CKD (Devraj & Gordon 2009) and despite the delay in recognising the importance of health literacy within the nephrology community, there is now a growing movement devoted to this issue in CKD primary health care management (Devraj & Gordon 2009). The aim of primary health care CKD management is the preservation of residual kidney function with the expectation that the person will participate in preventative care and present for further medical management when deteriorating kidney function symptoms are recognised (Campbell, Woods & Sankey 2008). Primary health care education prepares the person to self-administer oral medications, subcutaneous Erythropoietin and/or insulin and successfully manage their complex diet and fluid restrictions correctly so as to avert complications (Campbell et al. 2008; Devraj & Gordon 2009; Sakraida & Robinson 2009). Diabetes mellitus primary health care management requires the person to understand a multitude of concepts and skills communicated by a team of health professionals to successfully carry out preventative self-care health behaviours (Schillinger et al. 2002). Similarly, to people with diabetes mellitus, people with CKD, and those with diabetes mellitus complicated by CKD, must participate in education to assist them in managing their challenging medication regimens (Sakraida & Robinson 2009).

People with end stage CKD are often placed in a situation where they are required to make a choice to commence renal replacement therapy without having any previous experience of these therapies. How they will feel emotionally and manage

to cope with an unpredictable future state of health is also unknown. Additionally, information is sometimes provided while the person with CKD is in a highly anxious and emotional state that may hinder the ability to ask questions, process information and make appropriate and well-informed decisions (Katz et al. 2006; McCaffery et al. 2007). Decision making is an area of nursing research that has been conceptualized along a spectrum from passivity where nephrology health care professionals make decisions on that person's behalf without consultation to active involvement, where people make independent health care decisions (Manias & Williams 2008). According to Eyler & Jeste (2006) there are four elements in the decision making process when making an informed health care decision; understanding, appreciation, reasoning and choice. Understanding involves more than knowledge acquisition but an ability to comprehend and analyse the information being delivered. This element of decision making is an issue for people with CKD who may not have sufficient health literacy skills as a result of limited English language skills or cognitive impairment. Appreciation involves an awareness of the relevance of the information to the person's own personal wellbeing and is subject to emotional factors that influence that person's belief system or world view. Reasoning is the ability of the person to weigh the risks and benefits of their participation in the process and requires sufficient cognitive processes where complex information is memorised and analysed at the same time. Choice involves the person being able to communicate to others their decision in a clear and unambiguous way and is strongly linked to positive feelings of autonomy (Deci & Ryan 2000).

CKD is now recognised as an independent risk factor for cognitive impairment (Elias et al. 2009; Madero, Gul & Sarnak 2009) where there is a disturbance in any two areas of cognitive function which include memory, verbal learning, executive functioning, attention or speed of information processing, perceptual motor abilities or language (Elias et al.

2009; Madero et al. 2008). Impairments in cognitive function are known to influence decision making capacity (Madero et al. 2008) and therefore contribute to the limited health literacy found in people with CKD. A study by Kurella et al. (2004) found a significant difference in cognitive scores in people with CKD compared to published matched norms and the severity of cognitive impairment was directly related to the stage of CKD. Of particular interest to nephrology nurses involved in health care education, even modest decreases in kidney function have been found to be associated with lower levels of performance in cognitive functioning therefore affecting the ability to process and retain information (National Collaborating Centre for Chronic Conditions 2008; Elias et al. 2009; Khatri et al. 2009; Madero et al. 2009). Causes of cognitive impairment in CKD have been identified within the major category of cardiovascular disease which includes atherosclerosis, clinical stroke, silent stroke, hypertension, diabetes and hypercholesterolaemia (Elias et al. 2009). Other possible causes include untreated anaemia, hyperparathyroidism, aluminium intoxication, polypharmacy, sleep disturbances and/or depression (Madero et al. 2009).

A study by Grubbs et al. (2008) found that people on dialysis with limited health literacy were 78% less likely to be referred for a renal transplant. These findings are important as both pre-emptive living related and cadaveric renal transplantation should be discussed as a treatment option for the person with late stage CKD, along with dialysis and conservative therapy (Fink 2008). Therefore health literacy has been suggested as a possible cause for the failure of people with CKD to access the transplantation pathway due to the inability to be a major stakeholder in the process (Fink 1998; Devraj & Gordon 2009). To confirm the importance of health literacy to health outcomes in this population, a study by Gordon and Wolf (2009) found that renal transplant recipients with limited health literacy were found to have a higher serum creatinine than those with adequate health literacy. This may be due to the challenge renal transplant recipients with

limited health literacy have in managing their post transplant health, including adherence to complex immunosuppressant therapies and recognition of rejection (Chisholm et al. 2007). Gaston et al. (1999) reported that errors in the self administration of immunosuppressive medications resulted in a graft loss of 35%.

### Screening for Health Literacy

Years of school completed is an inaccurate measure of true educational attainment because many individuals progress through the educational system without meeting desired goals such as reading fluency (Baker et al. 1998; Adams et al. 2009). Additionally, older people should not be assessed for literacy by this method due to the time lapsed since attending formal school together with age related declines in reading fluency (Baker et al. 2007). Primary health care education should include screening for health literacy capabilities prior to the provision of any education (Tang et al. 2008; Jeppensen et al. 2009).

People with limited health literacy may feel that the quality of their experiences with health professionals may be lacking due to ineffective communication when being provided with instructions. This could be further compounded by a lack of accessible and easily understood health information resources (Wolf et al. 2005; Gazmararian et al. 2006). An understanding of the potential for limited health literacy in people with CKD can encourage nephrology nurses to adjust their communication styles and educational materials so as to improve the health professional interaction experience (Cordasco et al. 2009; Adams 2009). Potentially an improved health professional interaction and learning experience will assist people with CKD to better manage their complex health regimens with the ultimate aim of improved health outcomes which include the successful preservation of kidney health (Becker 2009; Devraj & Gordon 2009).

Nephrology nurses need to remain sensitive to the possibility that people with limited health literacy may feel threatened,

embarrassed or ashamed by the disclosure of their limited health literacy while others may be unaware of their limited health literacy skills (Davis et al. 2002; Wallace et al. 2006; Wolf et al. 2007) Informal clues that may indicate that the person with CKD has limited health literacy include; attending for appointments on the wrong day or time, making excuses for not reading information provided at an earlier appointment and an inability to discuss medication timetables (Cassey 2007). People with CKD with limited health literacy may be ashamed to ask for assistance or may leave an information session with unanswered questions due to embarrassment in asking for the information to be repeated in a simpler form (Adams et al. 2009; Devraj & Gordon 2009). They may use a surrogate reader such as a family member or friend to read information provided (Davis & Wolf 2004). Screening for health literacy skills needs to be undertaken with sensitivity by the nephrology nurse as the potential for disclosure of poor health literacy may increase feelings of shame creating internal conflict. This may have an adverse impact for those who already face barriers to accessing health care information and health care services (Wolf et al. 2007).

Various measurement tools are currently available to screen for health literacy. The most common three screening tools currently available are the Rapid Estimate of Adult Literacy in Medicine (REALM), the Short Test of Functional Health Literacy in Adults (S-TOFHLA) and the Newest Vital Sign (NVS). The REALM is a validated assessment of health literacy (Davis et al. 1993). The screening tool requires the participant to recognise and pronounce 66 words in a medically relevant vocabulary that is arranged in increasing order of difficulty (Owen et al. 2009). The REALM score is calculated by awarding one mark for each correctly pronounced word and zero for each mispronounced or skipped word. A score of 59 or less is defined as indicating limited health literacy while a score of 60 or more indicates adequate health literacy (Ibrahim et al. 2008). This instrument, which correlates highly with S-TOFHLA

(Chisholm et al. 2007; Ibrahim et al. 2008), is the most frequently used method to determine the level of health literacy. The tool requires minimal training to use, takes approximately 2-3 minutes to administer and is presented in a non-threatening format (Paasche-Orlow et al. 2005; Safeer & Keenan 2005). Muir et al. (2006) was able to demonstrate a positive relationship between limited health literacy and medication adherence as measured by the REALM in Glaucoma management and Kleinpeter (2003) administered the REALM to a peritoneal dialysis population and found that limited health literacy was evident in their population. Recently, this tool has been modified for use in the CKD population with transplantation concepts and words and is known as the REALM-T (Gordon & Wolf 2009).

The S-TOFHLA is a seven-minute screening tool, which comprises 36 item multiple-choice questions to assess reading comprehension and numeracy ability (Chisholm et al. 2007). This health literacy screening tool has been used in a population of people with diabetes mellitus where 29% of participants were found to have limited health literacy. The NVS is a three-minute health literacy screening tool that comprises six questions related to nutritional information contained on an ice cream label. Participants are required to read and understand text as well as perform numerical calculations. Weiss et al. (2005) analysed the psychometric properties of the NVS and found that this screening tool could have more sensitivity than the S-TOFHLA in recognising limited health literacy.

### **Strategies to Increase Health Literacy**

High reading demands are required in complex medical conditions (Paasche-Orlow et al. 2005) and this is relevant to the CKD population as nephrology nurses rely on written information to reinforce verbal education provided. This reliance on written materials presents particular challenges for people with CKD, particularly in the older population who may have cognition,

vision and hearing difficulties (Safeer & Keenan 2005). Understanding the person's health literacy capabilities is crucial in the development of successful chronic disease self-management educational materials and services (Cordasco et al. 2007). Patient education materials may be inadvertently too complex, written at too high a level or not organised from the patient's perspective (Safeer and Keenan 2005; Wolf et al. 2005). Difficult language without definition and explanation, complex sentence structure and assumed knowledge may present insurmountable problems for those with limited health literacy and are therefore impediments to primary health care education (Zarcadoolas et al. 2005).

An increase in awareness of the implications of limited health literacy in primary health care education has led to the development of a 'clear language' movement (Zarcadoolas et al. 2005). In relation to the unique educational needs of people with CKD, Elias et al. (2009) has suggested that well organised and specific information would be able to be remembered by people with early CKD, however higher order critical analysis and problem solving remains problematic. Those with late stage CKD would be more vulnerable to difficulties processing and remembering information. Therefore primary health care information should be explained slowly, in small increments, using plain non-medical language utilising pictures with a repeat back phase to ensure understanding (Cassey 2007; Kountz 2009). People with CKD need to have both written and verbal information presented in a simple and clear format to facilitate understanding of their disease process and self-management treatment options (Davis et al. 2002; Hill-Briggs & Smith 2008). Safeer and Keenan (2005) have recommended that educational materials should be adapted to appear more appealing by using short, clear and simple text with the inclusion of pictures. Educational materials should be written at a reading level of sixth grade or lower to assist comprehension, use large fonts and leave substantial blank or white space to

give the text the impression that it is easier to read (Davis et al. 2002; Neilsen-Bohlman et al. 2004). Owen et al. (2009) reported that their CKD patient education materials were redesigned and modified and on reassessment there was an increase in the readability of the materials.

### Future Nephrology Nursing Research

Contemporary work in the area of health literacy examined for this paper has made a significant and timely contribution to our understanding of this important aspect of the experience of primary health care CKD self management. As health literacy is a relatively new concept, the literature about the relationship between health literacy and nursing care outcomes is still to be written (Speros 2005). Much of the recent work is exploratory in nature, providing a platform on which to more fully explore the issues surrounding primary health care education. Future nephrology nursing research is an ideal vehicle to promote health literacy research specifically in the CKD population to determine the influence of health literacy in relation to self-care management decisions and health outcomes for this population. Determining if only the ability to communicate orally with nephrology health care professionals has the same health outcomes as the additional ability to comprehend written information is an important next step in exploring health literacy in the self management of CKD (Bennett et al. 2009). Additionally, future health literacy research has the potential to identify specific barriers for people with CKD in seeking out primary health or acute care services (Wolf et al. 2005). Finally it is recommended that current health literacy screening tools be further modified to accurately assess the health literacy capabilities of the differing CKD populations due to their unique and complex knowledge needs (Devraj & Gordon 2009).

### Conclusion

Health literacy has become an important issue in both national policy and research agendas. Health literacy is more than

just being able to read health care educative information, it also involves the development of skills aimed at improving comprehension and analysis of information to assist the person to successfully navigate the complex health care system. Limited health literacy has been identified as a potential contributor to poor health outcomes including poor CKD outcomes. However further research still needs to be undertaken to identify the full impact of limited health literacy on nephrology outcomes. Nephrology nursing research using any of the three identified screening tools (REALM, S-TOFHLA or NVS) on CKD populations will contribute to the body of knowledge related to the unique educational needs of the CKD population.

### Author contributions

SC was responsible for the concept of the paper, literature review and drafting of the manuscript while MD made critical revisions to the final paper.

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