Improving Adherence to Phosphate Management in Patients with Hyperphosphataemia



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Introduction

End stage renal failure is a chronic and restricting condition, which requires careful dietary management. Adherence is an issue for many patients across the board, from dietary management, to taking medication, to time spent on dialysis. Rates of general non-adherence in renal patients have been reported between 30 and 60 per cent. This article explores the importance of adherence, and why, despite the medical consequences of non-adherence, patients still struggle, offering a psychological perspective. There is a specific focus on phosphate management, as for many patients the benefits of taking phosphate-binders are not always apparent or obvious in the short-term. Practical suggestions on how you may approach such issues are made.

The importance of adherence

The National Institute of Health and Clinical Excellence have recently focused a guideline on medication adherence - promoting its importance.² This guideline examines how healthcare professionals may work with patients who do not adhere to treatment, indicating the need to involve patients in treatment decisions, with good communication skills and education. The guideline encourages healthcare professionals to adapt their approach to each patient and raises awareness that patients may chose not to adopt recommended medication regimes. When non-adherence occurs, it is essential that healthcare professionals discover the reasons for the individual patient, including barriers, beliefs, and concerns.

Adherence in hyperphosphataemia

In a review of 34 studies of non-adherence³ there was a variation in reported rates of non-adherence to phosphate-binding medication (22-74% patients non-adherent). In a qualitative study of patients' perspectives of phosphate-binding medication, patients were found to have gaps in understanding and confusion about the concept of phosphate control and the role of medication.4

A pilot study of psycho-educational intervention into nonadherence with phosphate-binders found that patient knowledge can be improved.5 The intervention consisted of a demonstration of phosphate-binder, binding with a phosphate solution in transparent plastic stomach-shaped container, along with a personalised leaflet for patients with information about phosphate, adverse effects of high phosphate, level control and efficient medication use. The intervention was successful in improving knowledge, which was sustained at four-month follow-up. However, there were no improvements in self-reported adherence or phosphate levels. Clearly there is still room for improvement.

Why adherence is important in huperphosphataemia

Serum levels of phosphorus should be maintained between 3.5 and 5.5 mg/dL (1.13 and 1.78 mmol/L) in those treated with haemodialysis or peritoneal dialysis.⁶ Prolonged hyperphosphatemia causes softtissue and vascular calcification and is associated with increased morbidity^{7, 8} and mortality.^{9, 10, 11} Calcification of coronary arteries, cardiac valves, and pulmonary tissues produces cardiac disease, a major cause of death in patients with CKD. $^{7.\,12.\,13.\,14.\,15}$ Therefore, the prevention of hyperphosphatemia and maintenance of serum phosphorus levels within the normal range is essential.

As a healthcare professional what can I do? The evidence for psychological factors in adherence

Renal failure is a long-term unremitting condition, with treatment that offers health maintenance rather than cure, thus there are potential psychological and social consequences. Research indicates that depression is common in renal failure. and that hospitalisation for psychiatric disorders is high compared to other health conditions.16

In my experience as a Clinical Psychologist in a renal service, many healthcare professionals are very concerned about patients' lack of adherence. Dietitians are often concerned they are doing something wrong or wonder if patients are deliberately not taking their advice. This leads to staff trying harder, but often achieving little other than frustration. Consequently, an understanding of the various factors that may cause a renal patient to struggle with adherence is important. It is also important to recognise that patients often feel judged in relation to adherence, feeling misunderstood in their struggle to adjust to a difficult and lifelong condition. Patients desire to have an agreed collaborative treatment plan rather than regimental adherence.

Two recent literature reviews of adherence in Renal Replacement Therapy (RRT)^{IB, 19} considered quality of relationships with staff and family, social support, and psychological distress as contributing towards adherence, but evidence has highlighted individual factors further:

Control

Lower levels of personal control, and an increased preference for information and involvement were found to be associated with poorer adherence.20

Coping style

Patients who adopt active coping strategies prefer more control with dialysis and are, therefore, better suited to home treatment.² This indicates non-adherence may be associated with poor matching of the patient preferences to dialysis type.

Illness beliefs

Patients' beliefs regarding their illness, gaps in knowledge and misconceptions have been linked to non-adherence. For example, misconceptions of the role of dialysis in managing diet and fluid intake can lead to individuals thinking that dialysis cleanses the body of the 'bad' foods, therefore these are acceptable.22

Leventhal's model of self-regulatory illness²³ suggests an individual considers the illness experience within the framework of five main beliefs:

- Identity (What do I have?)
- Cure/control
- Consequences

- Timeline (How long will it last?)
- Cause

The nature of these beliefs, together with an emotional response to illness shape how a person copes with the illness. In the renal population these illness beliefs were found to predict levels of self-care over and beyond clinical and medical factors.24 The emotional response was also found to predict non-adherence, but depression specifically did not.

In addition, the patient's belief about themselves within the illness has been shown to predict self-management behaviour. A concept known as self-efficacy,25 is the belief that one is capable of performing in a certain manner to attain certain goals, for example, "I am sure I can tolerate four hours on haemodialysis."

Involvement in treatment decisions Evidence suggests that patient-led decisions result in decreased mortality at four-year

Distress

follow-up.26

Depression has been linked to shortening of dialysis sessions.²⁷ Symptoms of clinical depression include poor motivation and hopelessness, suggesting a role of selfneglect.

Readiness and motivation

The Trans-theoretical Model of Change²⁸ (which informed motivational interviewing) postulates that individuals ascend through stages of readiness, dependent on whether they are thinking about change or ready to take action. Readiness to adapt a healthy behaviour is a balance of confidence in one's own abilities (self-efficacy) and knowledge of how important that change is.

Culture

An awareness of how different cultural factors may shape an individual's belief system and social support is important. An international study of renal patients29 found differences between countries in predictors of nonadherence.

Relationships to care

Evidence suggests that a good relationship can support adherence. For instance, patient satisfaction with doctors and renal staff was positively associated with attendance for dialysis and better biochemical outcomes in an African-American population.30 Impersonal treatment by healthcare professionals has linked to increased skipped haemodialysis treatments and is an indicator of increased risk for hospitalisation.31

Although not currently studied in the renal literature, there is an increasing interest in the role of patient attachment style as a mediating factor in adherence and self-care*. Diabetic patients with an avoidant attachment style (characterised by mistrust of others to provide care), had poorer

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relationships with healthcare professionals, and showed poorer adherence to glucose monitoring, poor diet, exercised less, and took medication less.31

*Attachment is a cognitive model which develops as a result of the relationships a person experiences over time that determines whether the individual deems themselves worthy of care and whether they can trust others to provide care.

Practical steps

Professionals should be warned not to take a 'one size fits all' approach to non-adherence, rather to consider the individual they are working with. Many of the suggestions that follow are integrated from my own experience, and from the Motivational Interviewing approach to healthcare,33 which has recently been suggested as an approach to engage kidney patients in better disease management.34

To support adherence, it is useful to:

- Increase your background knowledge of the patient: e.g. how does this patient like to receive information? What are his thoughts and beliefs about having renal failure?
- Work on your relationship over time with the patient: offering continuity and consistency of care, clarity of role, and build trust over time (a patient is unlikely to listen if they do not trust what you have to say).
- Assess readiness to hear information: if a patient has just started on a dialysis regime he may be struggling to adjust, and might not perceive phosphate control a priority. Your role is to slowly increase this sense of importance over time, asking permission to give information when you do so. A sliding scale can help assess this, e.g. "On a scale of 1-10, how important do you think it is to control your phosphate levels?"
- Help a person consider the pros and cons of changing to adherent behaviour.
- Help patients to gain a sense of future implications, by asking them to imagine what life might be like in five years' time if they decide to do nothing, in comparison to what life might be like if they choose to make changes.

- When the person has an increased awareness of the importance of adherence, he can then consider whether he feels it is possible. The dietitian's role here is to improve the individual's confidence in this: telling him it is possible, and affirming any efforts made so far. In addition, meeting others who are managing successfully may be useful here. If not possible, recounting how other patients have taken different approaches and succeeded.
- Be aware that telling a person off or telling them the worst case scenario is likely to increase a resistance to change in nonadherent behaviours, and will compromise your relationship with them. Instead, ask for the barriers to their adherence, and help the patient consider options.
- Increase the patient's control and involvement in treatment decisions. Agree on treatment goals and ensure treatment regimes are designed around patients' preferences, with active patient involvement.
- Keep things simple, accessible, and consider using a number of different ways of delivering information (e.g. written, verbal, visual, meeting other patients).
- Ensuring you are asking openly about adherence. For example, it is more important to ask: "How are you getting on with your phosphate-binders?" than "Are you taking your phosphate binders?" which allows for a patient to tell you what is really happening, rather than what you want to hear.
- An awareness of the patient's ongoing distress levels in relation to managing his condition is useful, and it may be beneficial to gain the opinion of your renal psychologist or counsellor if you have access to one.

Conclusion

Although the implications of non-adherence are clear, the reasons why this happens can vary from patient to patient. In order to support adherence with our patients, it is important that we find out as much as we can about his/her individual circumstances, thus enabling us to tailor our responses accordingly.

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References: 1. Christensen A, Ehler S, (2002). Psychological factors in end-stage renal disease: and emerging context for behavioural medicine research. Journal of Consulting and Clinical Psychology; 70: 712-724. 2. National Institute for Clinical Excellence, NICE (2009). Medicines adherence Involving patients in decisions about prescribed medicines and supporting adherence. Accessed online: www.nice.org.uk/nicemedia/pdf/CG76FullGuideline.pdf (June 2011). 3. Karamanidou C, et al (2008). A Systematic Review Of The Prevalence And Determinants of Nonadherence To Phosphate Binding Medication In Patients With End-stage Renal Disease. BMC Nephrology, 31(9): 2. 4. Karamanidou C, Weinman J, Horne R (2007). A qualitative in-depth study of barriers to adherence to phosphate-binding medication in a small cohort of haemodialysis patients. Poster presented at the World Congress of Nephrology, Rio de Janeiro, Brazil. 5. Karamanidou C, Weinman J, Horne R (2008). 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 British Journal of Health Psychology; 13: 205-14. 6. KDOQI Clinical Practice Guidelines for Bone Metabolism and Disease in Chronic Kidney Disease. Accessed online: http://www.kidney.org/professionals/kdoqi/guidelines_bone/guide3.htm (June 2011). 7. Marchais SJ, Metivier F, Guerin AP, London GM (1999). Association of hyperphosphataemia with haemodynamic disturbances in end-stage renal disease. Nephrology Dialysis Transplant; 14: 2178-2183. 8. Guerin AP, London GM, Marchais SJ, Metivier F (2000). Arterial stiffening and vascular calcifications in end-stage renal disease. Nephrology Dialysis Transplant; 15: 1014-1021. 9. Block GA, Hulbert-Shearon TÉ, Levin NW, Port FK (1998). Association of serum phosphorus and calcium? phosphate product with mortality risk in chronic hemodialysis patients: A national study. American Journal of Kidney Disease; 31: 607-617. 10. Lowrie EG, Lew NL (1990). Death risk in hemodialysis patients: The predictive value of commonly measured variables and an evaluation of death rate differences between facilities. American Journal of Kidney Disease; 15: 458-482. 11. Blacher J, Guerin AP, Pannier B, Marchais SJ, London GM (2001). Arterial calcifications, arterial stiffness, and cardiovascular risk in end-stage renal disease. Hypertension 38:938-942. 12. Ganesh SK, Stack AG, Levin NW, Hulbert-Shearon T, Port FK (2001) Association of elevated serum PD(4), Ca? PD(4) product, and parathyroid hormone with cardiac mortality risk in chronic hemodialysis patients. Journal of the American Society of Nephrology; 12: 2131-2138. 13. Rostand SG, Sanders C, Kirk KA, Rutsky EA, Fraser RG (1988). Myocardial calcification and cardiac dysfunction in chronic renal failure. American Journal of Medicine 85:651-657. 14. Katz AI, Hampers CL, Merrill JP (1969). Secondary hyperparathyroidism and renal osteodystrophy in chronic renal failure. Analysis of 195 patients, with observations on the effects of chronic dialysis, kidney transplantation and subtotal parathyroidectomy. Medicine (Baltimore) 48:333-374. 15. Raggi P, Reinmuller R, Chertow GM (2000). Cardiac calcification is prevalent and severe in ESRD patients as measured by electron beam CT scanning. Journal of the American Society of Nephrology 75A, (abstr A0405). 16. Kimmel P L, et al (1998). Psychiatric Illness in Patients with End-Stage Renal Disease. The American Journal of Medicine; 105. 214- 221. 17. McCarthy A, et al (2010). Compliance, normality, and the patient on peritoneal dialysis. Nephrology Nursing Journal; 37(3): 243- 250. 18. Baines L S & Jindal R M (2000). Non-Compliance in Patients Receiving Haemodialysis: An In-Depth Review. Nephron; 85(1): 1-7. 19. Morgan L (2001). A decade review: methods to improve adherence to the treatment among haemodialysis patients. EDTNA ERCA Journal; 27(1): 7-12. 20. Cvengros JA, Christensen AJ, & Lawton WJ (2004) The role of perceived control and preference for control in adherence to a chronic medical regimen. Annals of Behavioral Medicine; 27(3): 155-161. 21. Christensen A, (2000). Patient-by-treatment context interaction in chronic disease: A conceptual framework for the study of patient adherence. Psychosomatic Medicine; 62: 435- 443. 22. Krespi R et al (2004). Haemodialysis patients' beliefs about renal failure and its treatment. Patient education and counselling; 53: 189- 196. 23. Leventhal H et al (1997). Illness representations: theoretical foundations, in KJ Petrie, JA Weinman (eds). Perceptions of Health and Illness. Amsterdam: Harwood. 24. 0 Connor SM, Jardine AG, Millar K (2008). The prediction of self-care behaviors in end-stage renal disease patients using Leventhal's Self-Regulatory Model. Journal of Psychosomatic Research; 65, 191–200. 25. Bandura (1977). Self-efficacy: Toward a unifying theory of behaviour change. Psychological review; 84: 191-215. 26. McCarley P (2009). Patient empowerment and motivational interviewing: engaging patients to self-manage their own care. Nephrology Nursing Journal; 36 (4), 409-413. 27. Kutner NG, et al (2002). Psychosocial predictors of non-compliance in haemodialysis and peritoneal dialysis patients. Nephrology, Dialysis, Transplantation; 17: 93-99. 28. Prochaska JO, DiClemente CC (1982). Trantheoretical therapy: toward a more integrative model of change. Psychotherpay: Theory, research, and Practice; 19: 276-88. 29. Untas, et al (2011). The associations of social support and other psychosocial factors with mortality and quality of life in the dialysis outcomes and practice patterns study. Clinical Journal of the American Society of Nephrology; 6 (1): 142-152. 30. Kovac JA et al (2002). Patient satisfaction with care and behavioural compliance in end-stage renal disease patients treated with haemodialysis. American Journal of Kidney Diseases; 39 (6), 1236-1244. 31. Newmann JM, Litchfield WE (2005). Adequacy of dialysis: The patient's role and patient concerns. Seminars in Nephrology; 25 (2), 112-119. 32. Ciechanowski P S, et al (2001). The patient provider relationship: Attachment theory and adherence to treatment in diabetes. American Journal of Psychiatry; 158, 29 – 35. 33. Rollnick S, et al (2010). Motivational interviewing. BMJ 2010;340:c1900 34. Martino S (2011). Motivational interviewing to engage patients in chronic kidney disease management. Blood Purification; 31: 77-81.