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## **GUEST EDITORIAL: Capturing Whole Person Care**

Andrew Morris<sup>1</sup>, Deborah Biggerstaff<sup>2</sup>, Deborah Lycett<sup>3</sup>

<sup>1</sup>*Specialist Renal Dietitian, University Hospital Coventry, UK*

<sup>2</sup>*Senior Fellow, Division of Health Sciences, Warwick Medical School, University of Warwick, UK*

<sup>3</sup>*Reader in Nutrition, Dietetics and Spiritual Health, Coventry University, UK.*

Biochemical blood levels are one international renal outcome measure. These quantitative data (such as phosphate levels) reflect, in part, dietary intervention and compliance to medical regimens, for example dialysis prescriptions and phosphate binding medication. The numbers demonstrate intervention efficacy, the cornerstone of evidence-based practice (EBP) (Greenhalgh et al., 2014). However, such data misses opportunities to capture the quality of the whole care provided, something that really matters to patients.

According to the international renal care recommendations, a whole person approach in renal treatment includes appropriate social, physical and spiritual care (Kidney Health, 2013; KDOQI, 2002; KHA, 2016) all elements which are the cornerstone of compassionate care (DH, 2015). One recommendation to inform an holistic approach to care is professional-patient research partnerships, which utilise mixed methodology to increase wellbeing within people's health journeys. For example, de-medicalising the clinical renal environment by using art and architecture (Tomlinson et al., 2015) is believed to enhance wellbeing since such an environment addresses the emotional and social needs of patients (Ebrahimi et al., 2013).

However, there are specific social, physical, spiritual and emotional needs, which impact dietary intake: all of these, and the interaction between them, therefore need to be addressed as part of dietetic care. An improvement in spiritual and emotional well-being, of feeling accepted, valued and understood may be a significant step along the journey to dietary adherence and improved biochemical parameters; however, these are not currently captured as outcomes. For example, patient well-being and confidence improves as patients gain more understanding and become more accepting of renal failure. This can be achieved through health professionals taking clinical time to get to know their patients and discuss the support their patients may need (Huntingdon et al., 2015).

Moreover, introducing a phosphate within international renal guidelines (KDIGO, 2009), may not illuminate the 'whole person' aspects of care delivery. For example, people may avoid social situations due to problems with dealing with such phosphate restrictions on a day-to-day basis (Morris et al., 2015). While their phosphate levels may be good, attracting positive feedback from health professionals, our patients may be in a poor state of mental

well-being through feeling isolated and misunderstood: areas which may not currently be captured in routine clinical renal reviews (Coombes et al., 2013). What seems to be required is an outcome measure that gives a more holistic picture of patient care. The question we then need to ask is: How might these more holistic aspects of care be attained?

Patient Reported Outcome Measures (PROMS) give an indication of how people are coping with the practical skills needed for every-day activities such as food preparation, in light of fatigue, for example (Gibbons and Fitzpatrick, 2010). The Renal Quality of Life profile (RQLP) may be a useful tool for these patients; it is a 43 item questionnaire with a 5 point Likert scale for responses. Five dimensions are explored: eating and drinking, physical activities, leisure time, psychosocial activities and impact of treatment (Salek, 1999). Patient Reported Experience Measures (PREMS) attempt to capture how 'satisfied' people are with receiving dietary advice, a measure of the interpersonal professional relationships, and therefore future service engagement (Morris et al., 2015).

Patient Activation Measures (PAM) may offer a solution to capturing the whole person care experience. PAM 13 item questionnaires are quick and easy to administer and capture quantitative data which facilitates a qualitative approach to clinical intervention (Greenhalgh et al., 2014). For example; a patient may feel that they disagree with the statement that they "are able to make appropriate dietary changes" post-renal transplant. The dietitian can then explore the feelings of insecurity as patients begin to liberalise their diet and adjust back to normal eating patterns. This qualitative, investigative approach exploring psychosocial reasons behind biochemical outcome measures has been shown to positively influence the well-being of people with other chronic conditions, for example, in exploring glycaemic control (HbA1c) for patients with diabetes (Kinmoth et al., 1998).

However, there may be other aspects of care, for instance, informal peer support in the outpatient clinic room, that are important to patients but which we cannot capture even with PROMS and PREMS. Systematic review of 28 studies using generic and disease specific SF-36 has shown an improvement in patient's lives, even without a relevant change to their PROM/PREM score (Gibbons, 2010). If an unknown part of service delivery exists which increases patients' wellbeing, then we need to know what this consists of in order that we can optimise our patient-centred evidence based practice and improve service delivery. These small, finely nuanced, but potentially important parts of the service delivered (directly or indirectly) may be captured by conducting qualitative research within this setting (Biggerstaff, 2012).

Such an approach to our work has much potential to inform all aspects of care, whether known or as yet unknown, and any aspects of care, that may be considered inconsequential by healthcare professionals, but be immensely valuable to the support and well-being of patients' themselves. Engaging with, and hearing from, patients in their own words about their lived-experiences is important as a way forward where we can learn about their point of view and gain a deeper understanding of how best to deliver quality care. We suggest

that by incorporating the voices and views of our patients by introducing more mixed methods and qualitative approaches into our research enquiry we can optimise the information we obtain to inform practice.

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