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Dialysis - Getting the Right Balance. A short report from a conference exploring the complexities of dialysis care provision

In this article, the authors outline a successful conference with stakeholders to explore the possible over and under-provision of dialysis in the NHS. The British Renal Society was one of the collaborating organisations involved in this event.

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On 27 November 2019, fifty-eight diverse stakeholders met in Bristol (UK) for a one-day conference, 'Dialysis – Getting the Right Balance'. The organisers, Barny Hole, Lucy Selman and Anna Winterbottom, share an interest in understanding and improving the experiences of people deciding which treatment to have for advanced kidney disease (Hole, 2017; Winterbottom et al., 2018; Selman, 2019). The conference was designed to identify the organisational changes, research and resources needed to address possible over- and under-provision of dialysis in the NHS.

What is already known?

Dialysis became available in the 1950s. Initially used in reversible kidney failure, it has been progressively provided to those not expected to recover kidney function (Cameron, 2002). Under-provision and rationing remained widespread for many years with most comorbid and older people with end-stage kidney disease (ESKD) dying without dialysis. Following prioritisation of renal services during the late 20th century, dialysis service provision was expanded (National Services Framework, 2004). Since the 1980s there has

been a persistent and sizeable rise in the number of older and comorbid people commencing treatment (Hole et al., 2018).

Whilst the abolition of unmet need is to be celebrated, concerns have arisen that some individuals may now be at risk of over-treatment (Grady, 2010; Moynahin, 2013; Born & Levinson, 2019). Dialysis carries considerable burdens in terms of time commitment, travel and disruption to everyday activities (Verberne et al., 2018). The survival benefit associated with dialysis depreciates with age and comorbidity (Hussain et al., 2013). The oldest and most unwell may not live longer on dialysis compared to those who choose to manage their symptoms with 'comprehensive conservative care' (CCC), which comprises all aspects of kidney management without dialysis (Murtagh et al., 2016). There is evidence that individuals accept shorter lives to avoid the burdens of dialysis, and that this underlies decisions to opt for CCC (Morton et al., 2010; Hole et al., 2016). Meanwhile, people approaching kidney failure report their preferences being overridden by family and clinicians and dialysis being prioritised over other options (Tonkin-Crine et al., 2015; Ladin et al., 2016; Selman et al., 2019). Wide variation in the kidney services available to this patient group reflect a lack of consensus and evidence regarding 'best practice' (Roderick et al., 2015).

It was from these parallel concerns relating to over- and under-treatment that the conference "Dialysis – getting the right balance" was born. The aim was to foster a collaborative network to engage in controversial discussion and begin to redress the potential imbalances in NHS kidney care. The objectives were to:

- Ascertain potential drivers of under- and over-treatment with dialysis
- Consider approaches to mitigate against these drivers
- Identify the resources and evidence needed to inform improvement

Pre-conference consultation

Prior to the conference, and to inform its content, the organisers consulted with members of the public, clinicians and other stakeholders. First, two patient and public involvement (PPI) events were run to develop conference content. Participants came from a wide range of backgrounds and ages, and included people with kidney disease, and those close to them. Areas of discussion included palliative and life-prolonging treatments and

individuals' preferences for each, and the idea of over- and under-treatment. Participants were disinclined to perceive 'life saving' treatments as potentially over-provided. Nevertheless, they discussed their own preferences for rehabilitative and palliative care, and recounted stories of what, in retrospect, they saw as futile and burdensome treatment of their deceased loved ones.

This pre-conference work highlighted that although over-treatment is a vogue topic in the academic medical literature, under-treatment was a greater concern amongst a non-professional audience. To further explore these opinions and identify topics for debate during the conference, a survey was distributed via the collaborating organisations (see *Acknowledgements*) using social media and email. Participants were asked to consider whether dialysis is over- and under-provided and if so, to identify what could be done to mitigate against this.

The 251 respondents included 87 people living with kidney disease and 7 carers, 133 health professionals (comprising 102 kidney and 16 non-kidney clinicians, and 15 others involved in healthcare delivery and research), and 24 'other' interested parties. Overall, 34% felt dialysis was under-provided, 41% did not and 24% were unsure. For over-provision, these were respectively 36%, 48% and 16%. Responses from people living with kidney disease (patients and carers) and the other groups were largely similar with respect to under-provision. However, there was a marked disparity with respect to over-provision, with just 16% of patients and carers answering that dialysis is over-provided, compared with 49% of the remaining respondents [Figure 1].

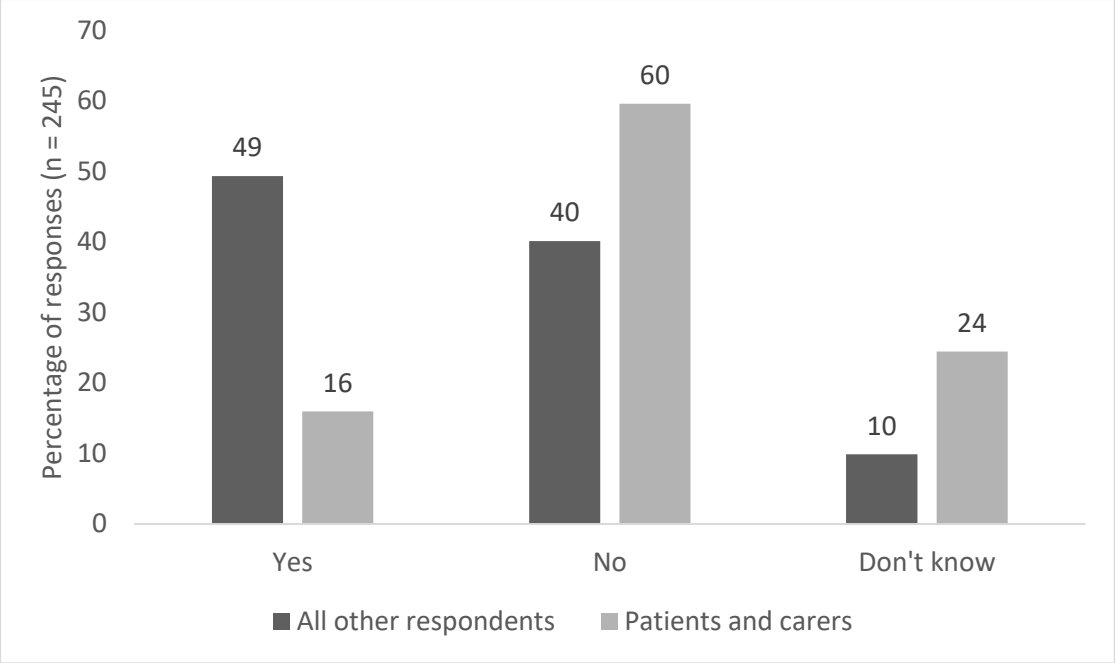

Figure 1: Do you believe that dialysis is over-provided to any individual or group in the NHS? *Bar chart showing 245 responses by respondent group: patients and carers (black, n = 94) and all others (grey, n = 151).*

Survey respondents were also asked the free-text question "What do you consider to be the greatest threats to balanced dialysis provision?" The qualitative responses were coded thematically to create an analytical framework of themes and subthemes [Figure 2].

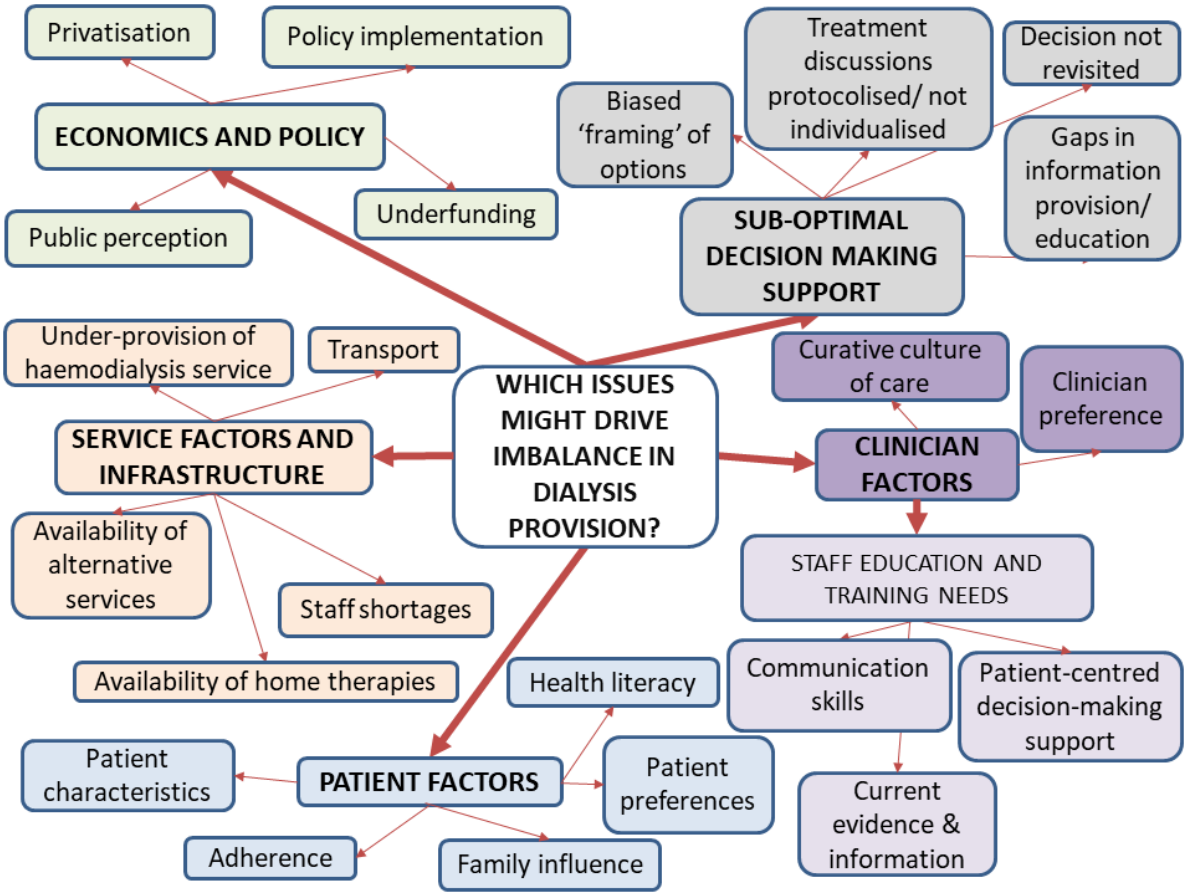

Figure 2: What do you consider to be the greatest threats to balanced dialysis provision? *Coding framework developed from free-text responses to the pre-conference survey question. Main themes: Economics and policy, Sub-optimal decision-making support, Clinician factors, Patient factors, Service factors and infrastructure*

The conference

The day opened with introductions and a summary of the survey findings. Subsequent conference activities were guided by the qualitative survey data. Delegates were given copies of a sample of the free-text responses and worked alone, then collaboratively, to classify these within the framework provided [Figure 2] and consider whether the response related to a driver of under- or over-treatment, or both. By the end of the exercise, delegates had coded and interpreted all 251 survey responses.

The morning session also included a presentation from a PPI member on the pre-conference meetings, and a 10-minute play developed from interview transcripts with older people facing the possibility of kidney failure. This piece was designed to highlight

the complexities of over- and under-treatment with 'life-saving' treatment from the patient perspective.

Following the morning's activities, delegates were allocated to five tables of mixed expertise. Each table was allocated one of the main themes from the coding of the survey responses [Figure 2] along with the response cards categorised under that theme. Each theme was discussed in detail, to identify drivers of over- and under-treatment and consider the approaches needed to mitigate against them. The whole group then developed recommendations in a facilitated discussion. The process and results will be published separately; however, preliminary recommendations included alignment of funding approaches for dialysis and CCC treatment, a need to recognise practice biases and reframe clinical decision-making around what is important to patients, and a requirement for higher quality evidence to inform clinical practice.

The conference closed with evening lectures. The organisers co-presented findings from qualitative studies of ESKD decision-making from patient and health professional perspectives. Hilary Bekker, Professor of Medical Decision Making at the University of Leeds, concluded with a keynote lecture entitled 'Helping people make balanced dialysis decisions'. Prof Bekker's talk included examples of how information can be presented in ways known to boost people's ability to make informed, shared decisions about their kidney treatment.

Conclusion and next steps

The conference and associated activities were successful in their aims. A collaborative, multidisciplinary stakeholder group was formed, and novel ideas relating to improving NHS kidney care were developed. Nevertheless, the challenges that lie ahead are substantial, and the conference raised more questions than answers. How can we judge whether the right amount of dialysis is available to those who want and need it? Why do such a large proportion of clinicians have concerns that we over-provide dialysis? Do the concerns from the patient and professional groups reflect important under-treatment?

A full report detailing the pre-conference questionnaire findings and recommendations will be published in due course.

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References

Born KB & Levinson W (2019) Choosing Wisely campaigns globally: A shared approach to tackling the problem of overuse in healthcare. *Journal of General and Family Medicine* 20, 9–12.

Cameron J.S. (2002). History of the Treatment of Renal Failure by Dialysis. Oxford University Press, UK.

Grady D (2010) Less Is More. How Less Health Care Can Result in Better Health. *Archives of Internal Medicine* 170, 749-750.

Hole B. The UNPACK study: Understanding treatment preferences of older Patients and their families deciding between dialysis and comprehensive conservative Care for Kidney failure. https://fundingawards.nihr.ac.uk/award/DRF-2017-10-127. NIHR Career Development Fellowship (2017-2021).

Hole, B., Gilg, J., Casula, A., Methven, S. & Castledine, C. (2018) UK Renal Registry 20th Annual Report: Chapter 1 UK Renal Replacement Therapy Adult Incidence in 2016: National and Centre-specific Analyses. *Nephron*. 139 Suppl 1, p.13-46.

Hole, B, Tonkin-Crine S, Caskey FJ. et al, (2016) Treatment of End-stage Kidney Failure without Renal Replacement Therapy. *Seminars in Dialysis* 29, 491-506.

Hussain JA, Mooney A, Russon L (2013) Comparison of survival analysis and palliative care involvement in patients aged over 70 years choosing conservative management or renal replacement therapy in advanced chronic kidney disease. *Palliative Medicine* 27, 829-39.

Ladin K, Lin N, & Hahn E. et al (2016) Engagement in decision-making and patient satisfaction: a qualitative study of older patients' perceptions of dialysis initiation and modality decisions. *Nephrology, Dialysis & Transplantation* 32, 1394-1401.

Morton, R.L, Tong A, Howard K, et al. (2010) The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies. *British Medical Journal* 340, c112.

Moynihan R, Glassock R & Doust J (2013) Chronic kidney disease controversy: how expanding definitions are unnecessarily labelling many people as diseased Ray Moynihan. *British Medical Journal* 347, f4298.

Murtagh FE, Burns A, Moranne O, et al. (2016) Supportive Care: Comprehensive Conservative Care in End-Stage Kidney Disease. *Clinical Journal of American Society of Nephrology* 11, 1909-1914

Roderick, P, Rayner H, Tonkin-Crine S, et al, (2015) A national study of practice patterns in UK renal units in the use of dialysis and conservative kidney management to treat people aged 75 years and over with chronic kidney failure. *Health Services and Delivery Research*, 3: 1-186.

Selman L, Bristowe K, Murtagh F (2019) The views and experiences of older people with conservatively managed renal failure: a qualitative study of communication, information and decision-making 2019 *BMC Nephrology* 20, 38.

Selman L. Optimising Staff-patient Communication in Advanced Renal Disease. https://www.kidneycareuk.org/news-and-campaigns/news/blog-dialysis-dilemma/ NIHR Career Development Fellowship (2019-2023).

The National Service Framework for Renal Services. Part One: Dialysis & Transplantation (2004). Department of Health, UK.

Tonkin-Crine, S, Okamoto I, Laden Gm et al, (2015) Understanding by older patients of dialysis and conservative management for chronic kidney failure. *American Journal of Kidney Diseases* 65, 443-450.

Verberne WR, Dijkers J, Kelder JC. (2018) Value-based evaluation of dialysis versus conservative care in older patients with advanced chronic kidney disease: a cohort study. *BMC Nephrology* 19, 205.

Winterbottom A, Bekker HL, Russon L, et al. (2018) Dialysis versus Conservative Management Decision Aid: study protocol. *Journal of Kidney Care* 3, 179-185.