

Resurgence in home haemodialysis: perspectives from the UK

Sandip Mitra¹, Mark Brady² and Donal O'Donoghue²

¹Department of Renal Medicine, Manchester Institute of Nephrology and Transplantation, The Royal Infirmary, Manchester, UK and

²Department of Health, London, UK

Correspondence and offprint requests to: Sandip Mitra; E-mail: Sandip.mitra@cmft.nhs.uk

Abstract

Improvement in dialysis outcomes requires a paradigm shift in haemodialysis provision and service design. Haemodialysis at home, recommended by the National Institute for Health and Clinical Excellence, can lead to outcome benefits but has a range of implementation barriers. This article describes the various initiatives in the UK at local, regional and national levels, to provide greater patient choice and autonomy, overcome adoption barriers and enable greater uptake of this modality.

Keywords: barriers; haemodialysis; home; initiatives

Dialysis for the treatment of advanced kidney disease can be hailed as a major success in health care technological innovation. Few life-saving medical inventions can rival its global uptake in the past four decades. The clinical community has embraced this by maximizing access to the treatment, which is mainly delivered by a skilled workforce using complex technology, in hospital-based and local community (satellite) dialysis clinics. A treatment originally set up in the 1970s, for financial and logistic reasons, as a home-based therapy, has become today centre based. This change in service delivery has been accompanied or facilitated by adaptations to treatment prescription. Slow longer dialysis regimens in patients' homes have been redesigned to offer shorter treatment sessions in-centre. While these provide adequate clearance of some retention molecules, efficacy is limited by the constraints of complex solute and fluid kinetics associated with rigid 4 h thrice-weekly schedules. Moreover, the publication of the HEMO study [1] has challenged clinical teams to search for alternative dialysis models directed at improving patient outcomes. Home haemodialysis (HHD) has re-emerged, in this context, providing new insight on how to improve patient outcomes. The clinical community within the National Health Service (NHS) in the UK has responded to this in a positive and effective way, particularly during the last 2 years, through a number of initiatives led by frontline staff, aimed at improving patient experience, cost-efficiency and dialysis outcomes.

National initiatives

In 2002, the National Institute for Health and Clinical Excellence (NICE) recommended that provided choice was of-

fered to all those clinically suitable, up to 15% of dialysis patients might choose to undertake HHD [2]. This seemed an attractive option, offering the potential to supplement a declining UK peritoneal dialysis (PD) population. At that stage, only a handful of UK units had HHD patients and UK HHD prevalence was at an historical low of ~1%. This, coupled with disappearing home training programmes, made NICE recommendations look ambitious and served notice of the challenges ahead.

In 2004, the Department of Health published *Part One of the National Service Framework (NSF) for Renal Services* [3]. This document followed on from similar documents addressing cardiovascular disease and diabetes care in the NHS. Unlike its predecessors, however, the renal NSF carried no specified additional funding resources. It set out five standards for dialysis and transplantation to be delivered by the NHS by 2014. Standard 4 stipulated that the delivery of high quality clinically appropriate forms of dialysis care should be designed around individual patient needs and preferences. The renal NSF also stated that NICE HHD guidance should be implemented ahead of the 2014 target.

The challenge was to provide improved patient choice for all approaching end-stage renal disease (ESRD) and greater involvement in the decision-making process. Based on the concepts of value-based medicine—where value for health care is addressed from a patient's perspective and across the full cycle of care [4]—the renal NSF also advocated timely preparation for ESRD treatment (Standard 3) to complement patient choice. Despite the lack of funding, the renal community has responded enthusiastically and successfully to the renal NSF, in particular through local clinical leadership and innovation, resulting in some tangible examples of improved care for kidney patients [5].

The last 3 years has seen the most significant change, with greater interest in HHD, from clinicians and especially from patients. This was ramified by the remarks of the Secretary of State in 2010, supporting the choice of patients to go home on dialysis and fully consonant with the thrust of Lord Darzi's report for 'Care Closer to Home' [6]. NHS Kidney Care was formed in 2008 as an improvement agency for the NHS, under the leadership of Beverley Matthews, to advance implementation of NSF standards. It has been at the forefront of recent developments, engaging the renal community, providing tools to improve choice for all kidney patients and

holding the aspiration that home therapies represent a genuine option for all suitable patients. In addition, the UK Renal Association has produced guidelines highlighting 10 drivers necessary for change [7].

The UK practices in HHD have been captured through the Renal Registry [8] and more recently in the Centre for Evidence-based Purchasing (CEP) report [9], which provides for the first time an overview of the HHD landscape and its provision. Forty-four units were surveyed through questionnaires (70% response), which provided information on practice patterns and service delivery. The uneven prevalence which emerged in many regions was not readily explained by demographics or other patient variables. Many units had restructured and integrated PD and HHD services—a logical approach. Transplantation (60.5%), death (18.3%), treatment failure (5.6%) and carer issues (4.2%) were the top four reasons for patients switching from HHD. Fear of cannulation seems to be a dominant factor in patients not choosing HHD therapy. The role of carers is vital but poorly understood and worthy of more attention. The Carers Week organized by NHS Kidney Care [10] is an example of the quest for solutions to such important issues.

Regional approach

The NHS in England is currently divided into 10 geographical Strategic Health Authorities (SHAs), with further divisions into 152 Primary Care Trusts. NHS Kidney Care has supported the formation of kidney care networks for each SHA, promoting local control while absorbing national learning. Renal services are commissioned for each SHA by their corresponding Specialized Commissioning Group (SCG).

In 2010, NHS Kidney Care and the Department of Health engaged directly with local patients, commissioners and clinical staff in each SHA, through these networks, organizing 1 day workshops entitled '*Improving Choice for Kidney Patients*'. These aimed to influence and empower local service redesign, to promote home therapies, bringing together key partners to address perceived barriers to change and identify collaborative strategic approaches to increasing home therapies provision. Drawing on work from several home therapy programme visits, patient stories, interviews and workshops at the annual home dialysis conference in Manchester, presentations, ideas and local issues were shared. The most influential and compelling elements were always the patient stories. In total, >300 delegates attended from 83 different NHS Trusts and 10 SCGs.

Following each event, a regional Action Plan was compiled, detailing key performance indicators to measure progress. Core themes identified include reducing inequity in treatment options, the need for integrated HHD pathways, availability of high-quality patient training and education, support for carers, the need to develop financial incentives and sustainability challenges [11]. A consistent theme is the need to challenge long held beliefs about who might be suitable for HHD. A recent analysis of outcomes for HHD patients in the UK between 1997 and 2005 demonstrated that HHD patients were more likely to be white, more likely to be wait-listed for transplantation (a surrogate marker for better health), less likely to be socially deprived and less likely to

have diabetic or hypertensive nephropathy [12]. Yet, we know that now many UK HHD programmes have patients who do not conform to the study population, including those who are successfully performing HHD with or without a carer and well into their 7th or 8th decade of life. A subsequent carers and patients workshop in January 2011 confirmed this need to challenge traditional views [10].

The true value of these initiatives will not be apparent for several years, but some regions have already made great strides. It seems apparent that where there is clear strong clinical leadership, progress is quicker.

Local centres

In the UK, by 2008, a reversal of the declining HHD trend appeared to have been achieved and HHD patient numbers have risen marginally since. The top three challenges in local units are: implementing a Cultural change in the approach to dialysis care, creating explicit Care pathways and encouraging the adoption of self-Cannulation (3Cs model). The Manchester programme is an example of such care in action. It has seen continued annual growth of HHD, having successfully trained 180 patients, with >70 prevalent patients at the end of 2010 (Figure 1), using a recruitment strategy inclusive of the whole spectrum of ESRD and by incorporating innovative solutions e.g. solo dialysis. HHD has been recognized by policy makers and health care organizations as a health care service innovation with great potential [13]. Many UK dialysis programmes show small but consistent increases in their HHD populations (Table 1) encompassing the establishment of new centres and the revitalization of mature programmes.

Economics

The high cost of ESRD treatment presents a major challenge. An epidemiological approach would suggest that a cost-effective intervention with health gain but a low uptake is a health improvement opportunity. An intervention yielding marginal gain in effectiveness at a high cost should be rejected; while one yielding high improvements in effectiveness at low cost should be readily adopted. Home dialysis fits into the latter category. Adoption, however, is typically a non-economic phenomenon and depends on time investment and bi-directional strategy, for patients and services.

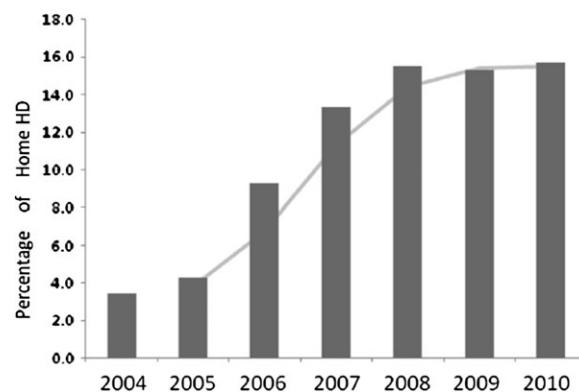


Fig. 1. Change in point prevalence for Manchester HHD programme (as percentage of all dialysis) during the period 2004–10.

Table 1. Demonstrating renal units with highest percentage of dialysis patients on HHD. [Source: UK Renal Registry, 11th and 12th Annual Reports 2008 and 2009, respectively]

Renal unit	% of dialysis patients on HHD on 31/12/2007	% of dialysis patients on HHD on 31/12/2008
Manchester	8.6	11.4
Brighton	5.5	5.7
Sheffield	5.2	5.7
Guys	5.1	5.1
Bristol	5.5	5.0
Preston	3.6	4.6
Derby	3.6	3.8
Birmingham Heartlands	3.6	3.2
Oxford	4.1	3.5
Hull	2.8	3.3
Newcastle	2.6	3.1
Liverpool Aintree	1.7	3.1

Challenges ahead

Most UK centres are committed to enable the choice of HHD. HHD is a complex care bundle that requires many ingredients for success, some clinical but others user-defined. To widen scope and opportunity, it is important to push boundaries recognizing that a more innovative approach to dialysis provision is necessary. Progress has been made, but much more needs to change, and this will require sustained effort from us all.

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