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Shared Care – A pathway for the rejuvenation of home haemodialysis?

A review of the evidence for promoting shared care dialysis to encourage the development of home haemodialysis

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There is considerable evidence from many years' research of the benefits to patients of being able to manage their own haemodialysis at home rather than being restricted to the thrice weekly model of most in-centre dialysis programmes. Patients have been shown in many studies to benefit both in terms of symptom control and quality of life indices yet in many dialysis centres only very few patients receive home haemodialysis (HHD) and a few centres have no evident programme at all (UK Renal Registry 2016).

In recent years much has been published about the development of shared or self-care programmes focussed on encouraging patients dialysing in-centre to take greater control over their own treatment, and the hope and expectation has been expressed that encouraging such autonomy would lead to increased numbers of patients opting to dialyse at home.

UK Renal Registry (UKRR) data from the eighteen annual reports produced from 1999 to 2016 shows that the percentage of prevalent dialysis patients receiving HHD was in more or less continual decline from 1993 until a low point of only one-percent of the dialysis population in 2002. The decline generally mirrors the ageing and increasingly co-morbid dialysis population and the expansion of satellite dialysis provision. Since 2008, according to the UKRR Reports there has been a steady increase and a return to the level of around four-percent of prevalent patients last seen in the mid-1990s (Figure 1). This period has largely coincided with the development of self-care and latterly shared care programmes in dialysis centres around the country and the development of smaller, more patient friendly home systems (Hignell & Gladding 2011).

There remains considerable variability in rates of HHD between different renal centres in the UK. According to UKRR data in 2014 there were eight units with less than one-percent of patients receiving home haemodialysis – and in five of

these the figure was zero-percent. On the other extreme, there were four units where over ten-percent of dialysis patients received home haemodialysis (Figure 2). Some of this variability can be explained by demographic and geographic differences between regions, North-west Wales for example is a geographically challenging area where access to even satellite units can be difficult for many patients. The same argument might, however be applied to other areas where UKRR data implies there are no or very few patients receiving HHD.

Most of the variation cannot be attributed to such external factors and presumably must largely reflect the treatment preferences and priorities decided by those managing these services. For example, Tong et al (2012) in a study of clinicians' beliefs about HHD in the UK and South America identified perceived barriers to HHD including; competing service priorities, safety concerns, carer burden, financial reimbursement structures and in many instances lack of knowledge and experience about HHD on the part of the participating clinicians. Despite these perceived barriers many in the study were able to identify potential lifestyle and clinical benefits of HHD.

Professional and organisational barriers to both HHD and shared care have been identified in a number of studies and common themes emerge despite the fact that most of the HHD studies focussed on physician attitudes whereas the shared care literature tends to focus on nurse attitudes (Figure 3). Significant commonalities across the studies relate to the impact of an operational culture within dialysis units linked to clinicians' perceptions that many patients would either not want greater involvement in their care or would be incapable of it. Linked to cultural factors were beliefs about clinicians not having sufficient time to train patients to manage their own care, although in both groups there were also concerns that increased patient involvement was a measure to reduce staff costs and numbers – a concern that has also been evinced in patient studies (Walker et al 2016). Patient and vascular access safety issues also feature in both barriers to HHD and shared care, often manifesting as an aversion on the part of clinicians to cede control to patients. This seems to be rooted in a medical model commonly summarised as 'doctor knows best' and on the nursing side what Davison and Cooke (2015) have identified as nurses having an entrenched view of themselves as carers rather than trainers. A further common perceived barrier to both HHD and shared care is a belief that patients would not be able to cope with the technical complexity of dialysis equipment, a belief that persists in spite of evidence to

the contrary and increasing availability of simpler, more patient friendly dialysis equipment (Hignell & Gladding 2011).

There are differences in the perceived barriers to HHD and shared care, which may largely reflect the differing professional profiles of those studied and specific differences between service delivery. Most studies into barriers to the provision of HHD were focussed on physicians' views and they often highlighted fears about inadequate patient education. In contrast most of the shared care studies focussed on the views of nursing staff and did not seem to view education as such a significant issue.

A key barrier to increasing HHD numbers is often cited as being unfavourable reimbursement regimes for home therapies, and this tends to be irrespective of the health service culture in which the study has been conducted. This is generally much less of a concern in shared care models where the patients would of course still be funded according to in-centre reimbursement rules. In the UK the British Renal Society has recognised these reimbursement challenges to HHD and has both produced guidance for renal centres and lobbied NHS England to introduce a funding model more favourable to home therapies generally (BRS 2015).

As well as professional and institutional barriers to HHD and shared care a number of studies have also identified patient concerns that may discourage people from taking on more of their own care. Responses from home and in-centre dialysis patients in New Zealand (Walker et al 2016) indicate that from their perspective, significant barriers to opting for HHD were fear and information deficit, which some of the respondents felt could be alleviated by the opportunity to engage in shared care dialysis. Patient anxiety related to shared care often centres around family support, self-cannulation and machine related technophobia (Wong et al 2015). Similar barriers are reported for HHD programmes (Rajkomar et al 2014, Blandford et al 2015) so it would seem reasonable to expect that overcoming such barriers in shared care programmes would have a knock-on effect to encouraging more patients to opt for HHD. Walker et al (2016) also identified patient concerns that encouragement to shared care and HHD were part of an agenda to save money and reduce staff numbers by coercing patients to take-over activities traditionally performed by dialysis nursing staff. There is clearly a significant overlap between the concerns of patients and those expressed by nurses and physicians, particularly with respect to the technical aspects of dialysis

treatment, safety concerns, patient education and access management fears. Such overlaps would seem to suggest that measures to alleviate professional concerns would in many instances also serve to address the fears often expressed by patients.

Much of the literature on shared haemodialysis care sees its promotion as at least part of a means of encouraging growth in HHD numbers (Wong et al 2015, Davison & Cooke 2015, Dainton & Wilkie 2013, Barnes et al 2013). Most of this work is, however focussed on the development of the shared care programmes themselves with an added aspiration to see increased HHD numbers. There is limited research on whether such aspirations have been realised.

It might be expected to find evidence from the Registry data that centres which have a record of actively promoting shared care also tend to record higher levels of HHD. The UKRR does not currently record data relating to shared care activity but a review of the UK renal centres publishing on the introduction of shared care initiatives in the last ten years might provide a clue as to whether such an assertion would be valid.

There have been around ten shared care HD initiatives reported in the literature in the last decade (Davison et al 2015, Davison & Cooke 2015, Wong et al 2015, Appleby 2013, Barnes et al 2013, Dainton & Wilkie 2013, Davison et al 2013, Glidewell et al 2013, Johansson 2013, Tibbles et al 2009). This is of course not an exhaustive list of those units engaged in shared care promotion, merely the subset that have published on the subject. With one exception none of the units that have published on shared care are among those which according to the latest Renal Registry (UKRR 2016) data have in excess of 7% of their prevalent dialysis patients receiving HHD, though six out of eight of the units featured in the shared care literature have increased their HHD activity since 2008. The mean 59% increase in HHD numbers for this group compares to a figure of 105% for the UK as a whole (UKRR 2016, UKRR 2010). These figures might be taken as suggesting that there is no direct link between encouraging shared care and increased rates of HHD but much more research will be needed to establish whether this is genuinely so.

Anecdotally and from a limited number of qualitative studies there certainly does seem to be a link between patients engaging in shared care and ultimately opting for HHD. Appleby (2013) studied thirty-five patients enrolled on a pilot shared care programme introduced at one centre, seven of whom

ultimately transferred to HHD. The study concluded that the shared care programme led to increased HHD numbers though there is no comparable data presented for patients not involved in the shared care programme.

Evidence from both shared care and HHD indicate that patients benefit from the associated increased autonomy through a strengthened sense of self and generally improved quality of life. Monaro et al (2014) identified a loss of a sense of self – particularly through lost autonomy and ability to engage in ‘normal’ life activities as a powerful experience of many in-centre dialysis patients. Walker et al (2016) reported similar experiences of patients in their New Zealand study. Cases et al (2011) interviewed six HHD patients many of whom were able to reconstruct their preferred view of self through the increased autonomy and control that managing their own care gave them. Rygh et al (2012) in their Norwegian study found patients’ quality of life perceptions improved considerably on HHD when compared to their previous experience of in-centre dialysis. Glidewell et al (2013) found very similar positive effects on patients receiving shared care in dialysis units across the north of England.

There is considerable reporting of improved physiological outcomes from patients receiving HHD (Power & Ashby 2014) usually because of increased treatment duration and frequency. Such benefits might not so easily accrue to patients undergoing shared care as the treatment parameters are often unchanged. It is suggested that increased patient knowledge may itself produce a positive physiological effect but this is an area with very little research evidence to support any such claim.

Conclusions

Anecdotally the link between the development of haemodialysis shared care and increasing levels of HHD does seem compelling, and much has been made of the contention that increasing shared care will be the answer to the issue of poor and uneven take-up of HHD. There is little evidence, however, to support the supposed link between shared care and HHD in the current literature on either treatment option. What is clear is that both shared care and HHD derive psychological and quality of life advantages for haemodialysis patients. There is also evidence of improved physiological outcomes for HHD patients, but there is currently no such evidence for shared care patients. It is anticipated that

improved patient engagement by shared care patients would lead to better concordance with dietary and fluid restrictions which might produce certain physiological benefits, but research is necessary to confirm whether this is so.

Advancement of both shared care and HHD programmes have been shown to suffer from a number of, often cultural barriers which have been highlighted in a range of studies in varied healthcare environments worldwide. This leads to vast differences in engagement with such self-management programmes, such as continue to be evidenced in the latest UKRR (2016) report. There seems, both on the part of renal healthcare professionals and their patients to exist a considerable knowledge deficit with regard to the advantages of self-management which seems to manifest as a cultural inertia largely leading to the maintenance of the status quo in many centres.

Recognition of the barriers to introducing self-management of any sort is essential to the successful introduction of such programmes. If the cultural and patient related barriers are not successfully overcome the successful introduction of new programmes becomes near impossible and such programmes as are introduced will be hard to sustain. Greater sharing of best-practice by those centres in which self-management programmes have succeeded is therefore essential if the great inequalities in current provision are to be addressed and the overall engagement with HHD to be increased.

It seems reasonable to conclude therefore that the link between shared care and HHD has more to do with the urgent need for a change in the culture of many renal centres for both to become established than supposing that the introduction of shared care will somehow automatically result in increased levels of HHD. Even when shared care programmes are established there will not be a concomitant increase in HHD activity if the cultural barriers to its implementation are allowed to persist.

Whilst there is considerable evidence supporting the clinical and quality of life advantages of HHD there remains only limited such evidence for shared care and less still for any link between the two. There is therefore clearly a need for much more research into the benefits to patients of shared care and the degree to which it acts as a stimulus to the take-up of HHD.

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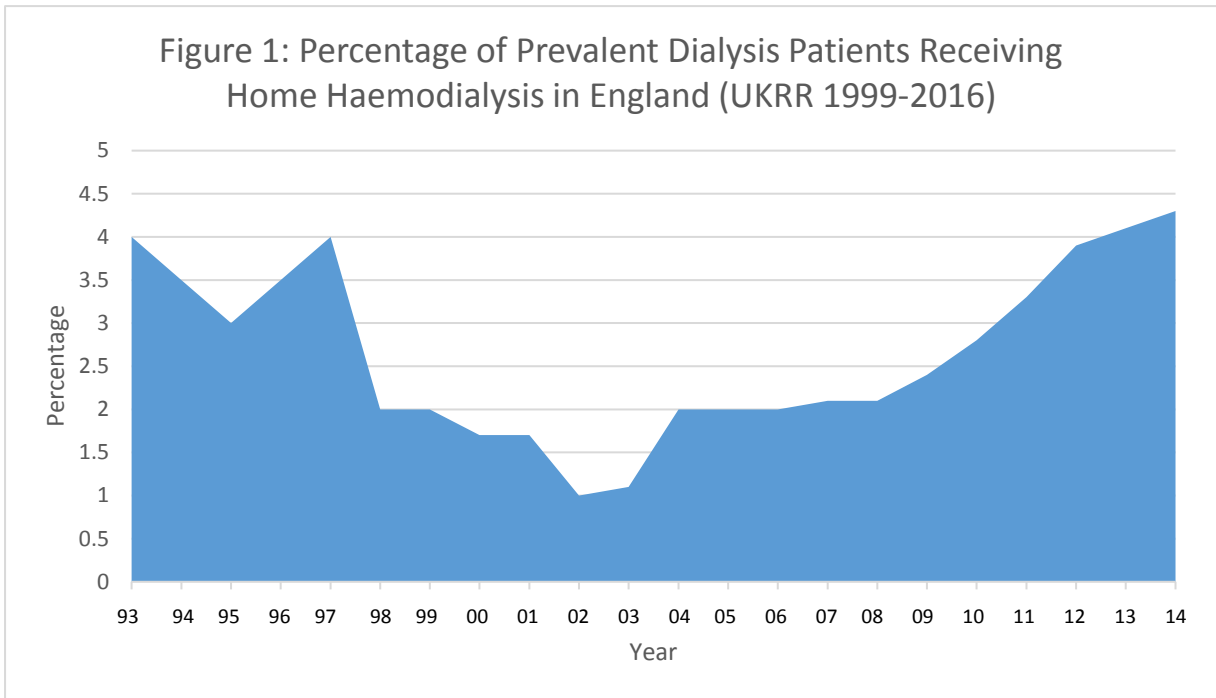
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Figure 1: Percentage of Prevalent Dialysis Patients Receiving Home Haemodialysis in England (UKRR 1999-2016)



*No data for 1994 or 1996. Data for 1993 and 1995 taken from text in the 5th UKRR Report (2003)

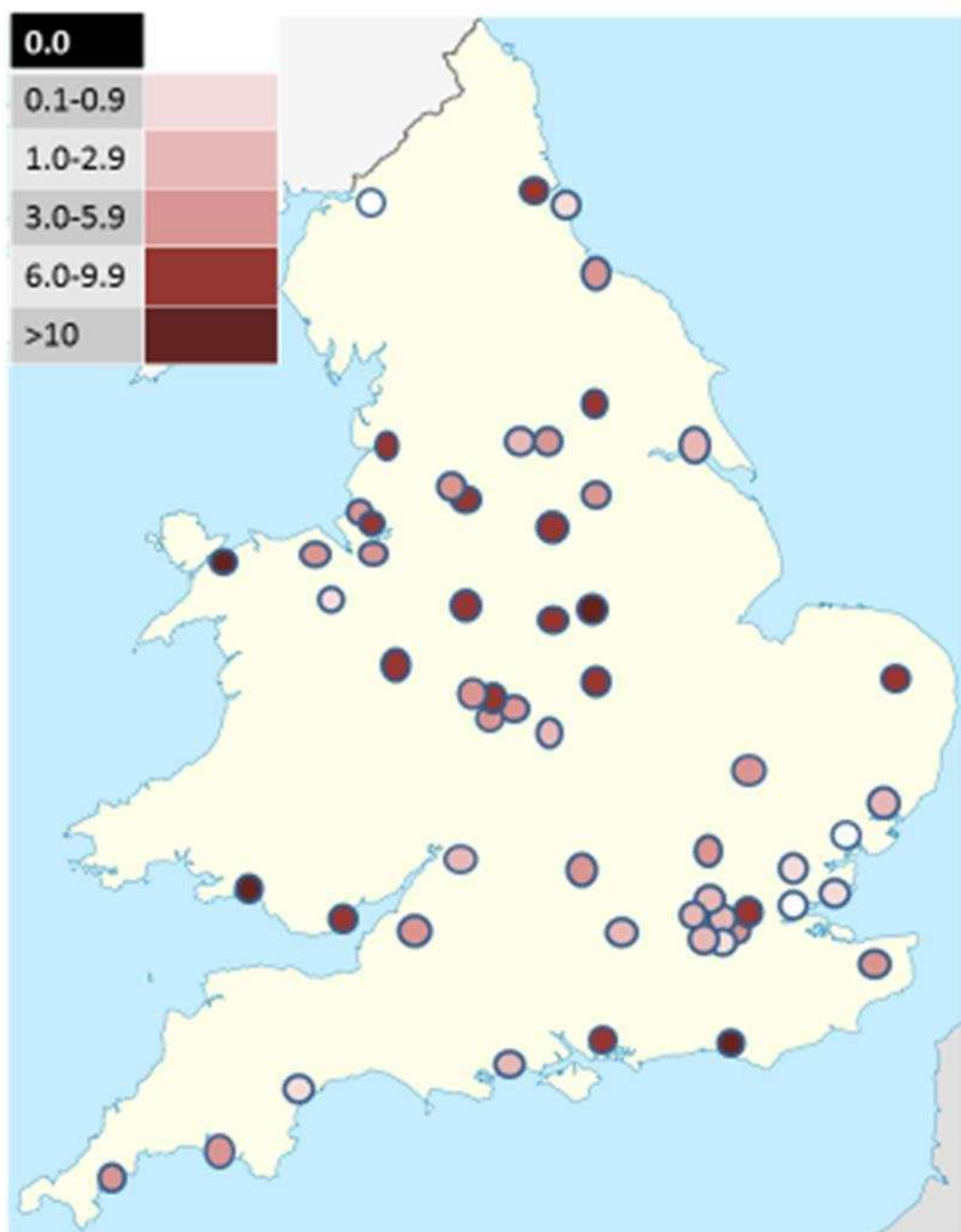


Figure 2. Percentage of prevalent haemodialysis dialysis patients who dialysed at home on 31/12/2014 (UKRR, 2016)

Barriers to HHD	Barriers to Shared Care
<ul style="list-style-type: none"> • Operational Culture • Lack of clinician skills and knowledge • Presumed lack of patient motivation • Clinician Bias • Poor patient education • Unfavourable reimbursement policies • Dialysis technology concerns • Patient safety concerns • Lack of clinician time • Lack of appropriate facilities • Vascular access concerns 	<ul style="list-style-type: none"> • Operational culture • Lack of clinician skills and knowledge • Presumed lack of patient motivation • Dialysis technology concerns • Patient safety concerns • Lack of clinician time • Vascular access concerns • Job security fears • Nurses' seeing themselves in the 'carer' role
Power & Ashby (2014), Jayanti et al (2013), Muroma-Kartunen (2013), Tong et al (2012), Ledebø (2008)	Davison & Cooke (2015), Dainton & Wilkie (2013), Glidewell et al (2013)

Figure 3: Comparison between reported barriers to HHD and shared care according to selected literature

