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## **Barriers and Enablers for older people to receive home haemodialysis – A Review of the Literature**

### **Background**

Recent publications and reviews have sought to explain and address the relatively low numbers of patients requiring renal replacement therapy (RRT) who opt for home-based therapies. This is especially true for home haemodialysis (HHD) where despite significant advances in terms of available technology the numbers of patients receiving these therapies remains obstinately low. According to Registry data only around 17% of RRT patients were on a home based therapy in 2015. HHD occupies only a minority share of even that small group with only around 4% of the total number of RRT patients across the UK. (UKRR 2017). These figures are mirrored in many other developed countries.

Sometimes the low numbers of patients receiving HHD has, at least in part been explained by the changing demographics of the dialysis population in most developed countries, the UK included. The rapid growth of dialysis programmes and ageing dialysis population together with the development of satellite dialysis units have been cited as reducing the need and demand for HHD.

If the dialysis population is ageing and there is an ambition to increase the numbers of patients receiving HHD it is therefore necessary to consider the barriers and enablers to more, older patients to have access to this therapy choice.

### **Prevalence**

According to the 19th Renal Registry Report (2017) there is a substantial differential between the median ages of those receiving HHD and those receiving peritoneal dialysis (PD) or in-centre haemodialysis (ICHD). According to the report, the median age for HHD patients is 55 years whereas the figures for PD and ICHD are 64 and 68 respectively. There is, however, considerable variation between units which suggests that any notion that older patients are inherently unsuitable for HHD would be erroneous. In one reporting area the median age for HHD patients was only 42 years, compared to 72 years for ICHD and 68 for PD. Five reporting areas, however, reported median ages for HHD that were actually higher than for PD and much closer to the figure for ICHD.

The Renal Registry (2017) do add a caveat to the reported figures because of the relatively small patient numbers in many instances, but they note that significant differences arise even when looking at units with larger numbers of home therapy patients. The report posits that non-patient related factors may be impacting patient numbers using home therapies generally, and if that is the case there is clearly an implication that local practice may point to both barriers and enablers to increasing the numbers of elderly patients receiving HHD.

The National Institute for Health and Care Excellence (NICE) (2002) recommend that all suitable patients should be offered a choice between HHD and ICHD. Suitable patients are described as those who have the ability and motivation to learn the necessary skills, are stable on treatment, relatively free of complicating co-morbidities, have good functioning vascular access, the availability of a carer and a suitable environment in which to dialyse. Whilst this guidance makes no mention of patients' age, the suitability list could be seen to mitigate against older patients who might be likely to have more co-morbid conditions and potentially less likely to have good vascular access. However, the inclusion of the need to be able to learn the treatment can be overcome through the use of trained carers and the criteria regarding stability do not really reflect the potential benefits of frequent or

slow nocturnal HD. The potential benefits of slower, home based, HD therapies for older people with multiple co-morbidities were recognised by Ross et al (2016)

## **Literature Review**

Research into home therapy access for older patients (aged 65 years or more) is limited and mostly tends to focus on PD rather than HHD, especially since the advent of assisted PD (aPD) programmes that have enabled greater numbers of older and co-morbid patients to access this therapy. An example of this was the BOLDE study (Brown et al, 2010) which concluded that quality of life (QoL) of elderly patients on PD was generally superior to that of those on ICHD.

Research into HHD, on the other hand, has generally not focussed on potential benefits to older patients, not least because of the small numbers generally involved. There is however, considerable evidence to support the benefits to patients of HHD generally, especially when patients use modified treatment regimens such as frequent/daily dialysis or slow nocturnal HD. A key advantage of HHD identified in recent years over ICHD is that patients dialysing more frequently, and avoiding the traditional post-weekend long interdialytic gap have significantly reduced morbidity and hospitalisation rates (Fotheringham et al, 2015).

An indicator of the paucity of research in this area is that a Cochrane review into home versus in-centre HD for elderly patients (Palmer et al, 2014) reviewed only one study of nine patients conducted in 2001. The review concluded that patients receiving slow HHD had improved blood pressure control and reduced risk of intradialytic hypotension. However, the reviewers also concluded that HHD patients reported more interference with social activities and greater carer burden than did patients receiving ICHD. Needless to say, the very small numbers in the study and the vintage of the reviewed research greatly limit the power of any conclusions that can be drawn from it.

Weinhandl et al (2016) reviewed over 4000 HHD patient records on the United States (US) data base matched with a similar number of PD patients. Their data suggested that daily HHD patients experienced lower levels of mortality, hospitalisation and technique failure than those receiving PD. Other studies have demonstrated improved biochemical parameters, reduced fatigue, lower rates of depression and improved QoL in patients receiving frequent HHD rather than ICHD (Palmer et al, 2014). It would seem sensible to postulate that if younger patients can derive such benefits from HHD then the same might also be true for older and frailer patients, possibly to a greater extent. Indeed a review of barriers and enablers to HHD in general (Sauve et al, 2016) identified the improved physical and mental well-being associated with HHD as a significant enabler to patients opting for this treatment modality. Closely linked to this as an enabler was the fact that HHD better enabled patients to maintain a normal life, in some ways contradicting Weinhandl's 2016 findings.

A review of the evidence by Nair (2016) included a case-study of a 76-year-old man with poor vision who successfully underwent training and commenced HHD using an NxStage machine. The patient became an ambassador for the company and travelled the country in that role, which would suggest that barriers to implementing HHD for older patients can be overcome.

In terms of actual research into enablers and barriers to older patients receiving HHD the evidence is limited at best. In a Canadian study Harwood and Clark (2014) interviewed 13 elderly (over 65) pre-dialysis patients and four of their healthcare professionals (HCPs) to assess the decision making process for ongoing treatment options. Four general themes emerged from the patient interviews, namely; precariousness with limited choices, personal factors, gender differences and the need for support.

Staff in particular listed precariousness or frailty as a key limiting factor in terms of therapy choices. Patients expressed similar concerns but also mentioned the hope that their dialysis treatment would help them feel better and regain some lost quality of life. Personal factors discussed by the patients included a lack of knowledge about the dialysis process. Various educational approaches were in use with the patients and there was no observed superiority of one form over another. With their lack of information patients often made their choice based primarily on which modality best suited their lifestyle rather than any consideration of which might serve them best clinically. Interestingly, many participants were keen to avoid the hospital environment and maintain their independence as much as possible – which would suggest a preference for home-based therapies. An interesting aspect of the study was observed gender variation; the women in the study appeared far more accepting of their need for treatment and were much more proactive in seeking out information in preparing for dialysis. According to the study, the most important enabler for HHD was the availability of support from the renal team and resources. Patients wanted the security of knowing that there would always be support available whenever anything went wrong or they had a question. The question of resources revolved around ability to pay to travel to dialysis centres and the possible need to pay for private nurses to assist in the delivery of their HHD, a concern which may be less relevant under the NHS than the Canadian system. HCPs had an acknowledged bias for therapy selection and admitted to trying to steer people away from making a choice for HHD if they felt it likely to be unsuccessful.

Harwood and Clark (2014) concluded that age alone should certainly not be a barrier to HHD but that in order to enable and facilitate older patients to select it as a treatment modality there is a need for adequate support and resourcing to be in place. Support may be informal, based upon family carers or organised professional support in the form of healthcare staff who could assist with the patients' dialysis treatment. Patients were often unwilling to lean on family members for support as they feared this may become burdensome to their families. The review of barriers and enablers to HHD in general by Sauve et al (2016) also identified support as the most important enabler to patients opting for HHD and noted the issue of the burden of care, often related to increasing age and frailty as a significant barrier. Technical issues associated with use of the dialysis equipment and ability to solve minor technical problems were also seen as a barrier by many patients, something which newer dialysis equipment specifically tailored for home use attempts to address.

A study into elderly patient satisfaction with both HHD and PD in New Zealand found high levels of patient satisfaction with both therapies and valued the independence that home therapies gave them. (Derrett et al, 2010).

Lack of knowledge about treatment options was also identified as a barrier to the take-up of HHD by patients of all ages in a review by Koester (2013). The review also concluded that age should not be a barrier to HHD, noting that the oldest person who had started HHD on their programme was 88 years-old. Morton et al (2010) in a systematic review of qualitative studies identified patient barriers to modality choices including; confronting mortality, fear of being a burden, decisions made by physicians, lack of resources and the influence of peers. Dialysis modality education is essential, and probably in a variety of formats, to cater for different patient learning styles. Bias from HCPs was a key factor mitigating against elderly patients opting for HHD, often because of assumptions about the degree of frailty and limitations due to co-morbidities of their patients. This sometimes meant education was biased towards the modalities that HCPs felt would be most appropriate for the patient.

It would appear that there is a historical bias against the potential to recruit elderly patients to HHD programmes, perhaps based upon outdated understanding of the technological and treatment regimen developments in recent years. For example, Johansson and Brown (2016) in a chapter on

choosing dialysis modalities for older patients describe an essentially binary choice between ICHD and PD, with no mention of HHD as a potential therapy choice for this group of patients.

## **Discussion and Conclusions**

Many of the barriers to increased uptake of HHD by older patients are the same barriers which mitigate against increased use of HHD generally. These specifically relate to clinician bias about the degree to which patients may be able to cope with a home-based therapy. Other barriers common in the research, regardless of patient age, include disruption caused by the burden of care, including disruption to the patient's home and family life as well as fears surrounding using the technology, isolation from clinical support, and vascular access. Barriers considered either harder to resolve or specific to older patients focus largely on frailty, complications created by co-morbidities and cognitive dysfunction related to the ageing process and dementia. Other identified barriers include lack of patient knowledge of their condition and treatment options and the possibility that older patients may be more resource intensive in terms of both initial training and ongoing support for HHD. These barriers have been summarised in figure 1 using the acronym 'DIFFICULT', developed from the themes in the literature: Disruption, Isolation, Fear, Frailty, Illness, Cognitive dysfunction, Unconscious bias, Learning deficit and Training availability.

Enablers for increased use of HHD in the elderly seek to address the barriers identified above, and as with the barriers many are common to all patient situations regardless of age. The most important enabler, regardless of patient age is support, encompassing; professional support from the renal care team, peer support from fellow patients and that provided by patients' families and carers. Shared Care or self-care models of dialysis provision are often cited as enablers to increased patient uptake of HHD but evidence to support the link is currently limited (Dainton, 2016). The provision of quality and effective patient education services, tailored to the varying needs of individual patients is a necessary enabler to overcome the barrier of patients who lack understanding about their condition and treatment options. Clearly, education for renal healthcare staff is also important in seeking to overcome the unconscious bias that so often mitigates against patients being considered for home therapies.

Possibly among the most significant enablers in seeking to extend HHD to older patients not previously thought suitable are the opportunities afforded through novel treatment regimens and new technology. It seems especially likely that treatment regimens such as slow nocturnal or daily short-session HD, which have been demonstrated to improve patient outcomes and QoL in all age groups, would make HHD a much more viable option for older patients. Additionally, new generation dialysis machinery specifically designed for home use, which often utilises cartridge systems for machine lining, together with the availability of remote monitoring systems may make HHD more suitable for older patients who might be less confident in dealing with the technology or have lower dexterity than younger patients. A further potential enabler, and area for research, relates to the challenge of vascular access in older patients, referred to by both patients and healthcare staff as a barrier. The development of safer connection technologies that minimise trauma and infection risk for elderly patients with relatively poor vascular access could prove a significant enabler to more patients accessing HHD. The enablers have also been summarised in figure 1 using the acronym 'STERN'.

In general, the greatest barrier to increasing numbers of patients engaging in HHD at all ages seems to remain an unconscious bias against the therapy choice, coupled with a perhaps over-cautious

attitude to decisions on patients' suitability. Dealing with this through education and training for those nurses and physicians involved in assisting patients to make dialysis modality choices may be the most effective way of increasing the numbers of older patients opting for HHD. Additionally, consideration and sharing of creative ways of facilitating HHD by patients traditionally unsuitable, in much the same way as has been achieved for PD patients with the adoption of aPD could also be a key enabler. It would be interesting to hear the experiences and strategies employed by those units who do already facilitate HHD by older patients in order to enable lessons to be learned and best practice spread.

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<b>'STERN' ENABLERS</b>	<b>'DIFFICULT' BARRIERS</b>
<b>SUPPORT</b> <ul style="list-style-type: none"> <li>• Professional &amp; technical</li> <li>• Peer support</li> <li>• Family/carer support</li> </ul>	<b>DISRUPTION</b> <ul style="list-style-type: none"> <li>• Burden of care</li> <li>• Changes to home/Lifestyle</li> <li>• Family dynamics</li> </ul>
<b>TECHNOLOGY</b> <ul style="list-style-type: none"> <li>• Dialysis equipment specifically designed for home use.</li> <li>• Remote monitoring of treatment from renal unit.</li> <li>• Visual communication</li> </ul>	<b>ISOLATION</b> <ul style="list-style-type: none"> <li>• From clinical experts</li> <li>• From other patients</li> </ul>
	<b>FEAR</b> <ul style="list-style-type: none"> <li>• Of the technology</li> <li>• Vascular access/invasion of the body</li> </ul>
<b>EDUCATION</b> <ul style="list-style-type: none"> <li>• Tailored to patient needs and age appropriate.</li> <li>• Use of Dialysis Modality Decision Aids</li> <li>• Staff education</li> </ul>	<b>FRAILITY</b> <ul style="list-style-type: none"> <li>• Loss of physical ability</li> </ul>
	<b>ILLNESS</b> <ul style="list-style-type: none"> <li>• Renal symptom burden</li> <li>• Co-morbidities</li> </ul>
<b>RESOURCES</b> <ul style="list-style-type: none"> <li>• Access to carers</li> <li>• Funding for home adaptation etc.</li> <li>• Funding for patient/carer support</li> </ul>	<b>COGNITIVE DYSFUNCTION</b> <ul style="list-style-type: none"> <li>• Dementia</li> </ul>
	<b>UNCONSCIOUS BIAS</b> <ul style="list-style-type: none"> <li>• Of nursing/medical staff</li> </ul>
<b>NOVEL TREATMENT REGIMENS</b> <ul style="list-style-type: none"> <li>• Short daily dialysis.</li> <li>• Nocturnal dialysis.</li> <li>• Vascular access solutions</li> </ul>	<b>LEARNING DEFICIT</b> <ul style="list-style-type: none"> <li>• Lack of patient knowledge of condition and treatment options</li> <li>• Staff training deficit</li> </ul>
	<b>TRAINING AVAILABILITY</b> <ul style="list-style-type: none"> <li>• Older patients may need more input and/or longer time to train.</li> </ul>

Figure 1: STERN Enablers and DIFFICULT barriers to HHD for older patients