Personal experiences of home haemodialysis: patients’ and carers’ experiences

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Abstract

The discussions from a patient-led session at a national home haemodialysis conference are described. A number of discussion themes are described, together with patients’ views on technical and social aspects of home dialysis. Issues highlighted included the preparation for home systems and the role of intrinsic motivation to change regimens and practice. A number of conclusions are drawn from the discussion, highlighting the role of patient beliefs about conducting haemodialysis at home.

Keywords: Home haemodialysis; carers; intrinsic motivation; beliefs

Report from a patient-led conference session

As part of the Manchester Home Dialysis conference in October 2010, a number of people using various home haemodialysis systems, together with their partners, presented their experiences and responded to questions from the floor. Two sessions were devoted to patient experiences, the first centring around the good and not so good experiences of the patients and their partners, the second centring on the advantages and disadvantages of specific home dialysis machines and systems.

Emergent themes

A number of messages became clear from the first session. The patients all described dialysing in their home environment and the flexibility of time as important factors in their choice to engage with home haemodialysis. They also—universally—praised the help and dedication provided by the nurses who supported them. They were felt to be very important in the success of the home systems.

However, patients’ partners reported feeling quite alone in their roles and that they often worried about aspects of the care they offered or the technical aspects of dialysis. Although they described regular contact with the nursing staff, they reported that it would have been good to have had access to other carers in some form of network. This can be beneficial in a number of ways. Firstly, such a network would provide a ready source of information that may be reassuring. Secondly, it facilitates the process of ‘normalization’ [1], in which anxieties are reduced when finding out that other people are having similar experiences and that the person is not alone in what they think and feel. The audience made a number of suggestions about how this could be facilitated.

Patients’ views on technical and psychosocial aspects of home haemodialysis

The second session involved a number of patients who were using diverse dialysis machines and systems describing their experiences and answering queries from the floor. Again, a number of common themes emerged, including the regaining of a social life due to the flexibility of dialysing at home, the technical challenges (sometimes requiring innovative solutions generated by the patients themselves!) and the differences in attitude and behaviour that being responsible for one’s own care brought about.

One of the most important processes highlighted from the discussions was the preparation routine for the home haemodialysis regime. Patients have to become familiar with a number of procedures in order to successfully and reliably implement them. These are not just the technical aspects of setting up and stripping down the machines but also the hygiene, dietary and needling regimen necessary. Self-needling can often be a significant psychological barrier to overcome for those using an arterio-venous fistula, as patients may overestimate the experience of pain or believe they will not be able to successfully ‘needle’ the fistula, among other factors. Patients therefore need to change a number of their own behaviours, becoming much more active in taking responsibility for their treatment. An important factor in the changing of behaviours is the moderation of attitudes or beliefs [2]. For example, many patients will not opt for home dialysis if they do not believe that the benefits (e.g. flexibility) will outweigh the costs (increased responsibility). These factors are often driven by the patient’s own values ([3]; e.g. if a patient highly values flexibility of lifestyle, they will be more likely to overcome the costs). Ultimately, the attitude change for...
patients should aim towards enhancing their self-efficacy, i.e. how effective they believe they can be in adopting a set of new behaviours and responsibilities [4].

Preparation for home haemodialysis

The nursing staff preparing patients for home haemodialysis clearly has a significant role in enabling patients to develop the attitudes and skills necessary for home treatment. In order to do this, they may need to elicit the patients’ beliefs, which may be barriers to considering the treatment. The experiences of the patients at the conference was wholly good—the nurses started to prepare some of the patients early and encouraged them to practice in the units in which they dialysed. This longer term build-up and gradual disengagement enabled the patients to be confident in their skills and more likely to be successful when treating themselves.

However, there is a rich vein of research indicating that perceptions of the need for patients’ control over their treatment varies widely [5], which may influence medical staff’s predisposition to facilitating independence. For example, hospital staff who believe that it is in the best interests of the patient for staff to maintain control over treatment, or who have not really considered the issue, may actually impede the effective treatment of those with long-term conditions who wish to become more independent. A growing body of research [6], indicates that people are much more likely to change behaviours if their motivation to change is ‘intrinsic’ (i.e. internal) rather than ‘extrinsic’ (i.e. situational or associated with some other agent). So, many patients are much more likely to change their behaviour if they can see the value in it rather than just being told that it will be a good idea. This is often called ‘Self-Determination Theory’.

Conclusions

What was clear from the reports of the patients is that they valued their independence, and for some at least, this independence was in no small part due to their own self-efficacious behaviours underpinned by beliefs that home dialysis provided a solution that enabled them to live their lives in accordance with their own values and priorities. They felt that the nurses and medical staff who supported them also promoted independence through training and ongoing attention. It may be that more patients could be engaged in considering self-management and dialysis if their beliefs and attitudes are made explicit and carefully considered.

Conflict of interest statement. None declared.

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