ACE: Acceptance, Choice and Empowerment - A Peer Educator based community project that aims to improve choice and quality of life for pre-dialysis patients.

Background

The uptake of home dialysis at The Heart of England Foundation Trust (HEFT), supported by a grant from Baxter Healthcare Ltd. The objective is to raise awareness about dialysis and especially home-based treatments, in order to address this issue, and evaluate using the charity’s well established and multi-award winning Peer Educator (PE) model to support patient decision making.

Objectives

ACE: Acceptance, Choice and Empowerment is a collaborative 15 month pilot project led by Kidney Research UK and the renal team at HEFT, supported by a grant from Baxter Healthcare Ltd. The objective is to raise awareness about dialysis and especially home-based treatments, in order to address this issue, and evaluate using the charity’s well established and multi-award winning Peer Educator (PE) model to support patient decision making.

Methods and progress to date

Ten Peer Educators, all with some experience of renal replacement therapy, have been recruited and trained to an accredited level (equivalent to a 1st year undergraduate) and have also shared experiences and bonded as a team.

A Peer Educator Coordinator oversees and manages the day to day deployment of the PEs and the model has been adapted in collaboration with the kidney failure nurse support team to facilitate patient acceptance, choice and empowerment. PEs are accompanying nursing staff in clinics where patients have the opportunity to talk to them about dialysis options and to learn more about life on dialysis. Home visits have followed in order to introduce dialysis options to patients in the context of their own lives. The Dialysis Decision Aid booklet developed by Dr Hilary Bekker and Kidney Research UK is an integral part of the project and training about its evidence base and usage has been provided for the project team by Dr Bekker. The booklet has been given to patients after their initial visit by the PE and nurse with follow up from the PE to continue facilitation of the outcome of the decision making process.

Standard operating procedures were developed to ensure consistency and help to facilitate future roll out and sustainability.

Results

Due to the poor uptake of places by Asian patients at previous HEFT patient information days, the team planned and delivered two bespoke Asian patient information events. It was held to decide the events on Saturdays at local venues in the community; rather than at the hospital, the usual venue. Peer Educators, alongside the Clinical Nurse Specialist speak about the various dialysis options, as well as kidney failure itself, about diet, social and financial benefits. A dialysis machine, including PD equipment are made available for demonstration as well as a display stand with relevant resource materials. Patients are allowed to bring a family member or friend and encouraged to ask questions throughout the presentations and during breaks and lunch which they do. We also found many spontaneous questions coming up among the patients and their carers. Patients are also given the choice of speaking in their own language with the PEs to facilitate direct communication. We have had some very encouraging results to date, indeed, the first event resulted in ten patients attending – this compares to an average of one from previous events! The feedback has also been very positive with patients and carers being asked to rate various aspects of the information (such as the length and content) between 1 and 5 (highest score). At the second event, a total score of 323 was achieved out of a maximum score of 330.

Conclusions and application to practice

Our previous work with Peer Educators is proven in effectiveness and has been commissioned by other funders and so we are optimistic that once we have completed the pilot and interpreted our findings we will be in a position to suggest solutions to this issue which will likely benefit patients, carers and the renal centres serving them. The reflective diaries of the Peer Educators and the highly positive feedback from the nursing staff and patients in clinics and at the information days, indicate that we are making excellent progress towards addressing the challenges of dialysis choices.

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References:

1. Kidney Research UK
2. Health of England
3. Foundation Trust (HEFT)
4. Baxter Healthcare Ltd

Comments received included...

Clear, precise, to the point
Very helpful, educational
Much better informed
A good variety, different individual experiences
Very informative and time to ask questions

Figure 1: Percentage of Patients on Peritoneal Dialysis (PD) at seven Renal Centres in the West Midlands

Figure 2: Sample content of the reflective diaries used by Peer Educators:

“I really enjoyed it; the patients were responsive. Some were asking all sorts of questions and others were a bit less responsive… I thought it all went well and took forward to my next clinic (male Pac PE)“.

“The patient found my advice very useful. Another one was assured and happy hearing it from someone already in his shoes but further down the line. His main question was going back home and explained how it would work and about isolation after coming back, but that would only happen in due course. Overall the two patients met with left happy with more information and felt supported (male Pac PE)“.

Figure 3: The ACE Peer Educator team at an Asian patient information event.