Development and Delivery of a Diverse Peer Support Programme for Renal Service Users, their Family and Carers: An Action Research Collaboration

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**Summary of project**
A Participant Action Research multidisciplinary and service user group was developed to unite diverse stakeholders, with wide ranging knowledge and experience, to develop a diverse peer support programme. Kidney peer support involves patients with kidney disease who have been trained to offer support, helping other patients with kidney disease who are facing similar situations, concerns and worries. This support can provide reassurance, increase confidence and help to find solutions.

Over an 18-month period, ten peer supporters with diverse treatment experience, were trained. Peer supporters contributed to patient information days, offered support to people who were starting dialysis in an unplanned manner, one-to-ones and as a co-applicant on a research bid. However, concomitant challenges arose, firstly embedding peer support in the wider renal service was limited and referrals from consultants remained low. Following commencement of peer support delivery: two patients were transplanted and returned to work; three were unreliable; the others changed their preferences for providing peer support, resulting in gaps in delivery; all compounded by chronic staffing shortages.

Developing a peer support programme requires service wide buy-in from the start. The nursing leads are now focusing on training individuals once they have established their commitment to, and preferences for, providing peer support in an informal capacity. By seeking funding from charity sources, it may be appropriate to train a service user to deliver peer support training and co-ordinate delivery. Importantly, our learning is feeding into a national NHS England and Renal Registry
programme around transforming participation in chronic kidney disease.

**Background**

University Hospitals Coventry & Warwickshire NHS Trust provides kidney care services for over 3,500 adults with renal disease. The multidisciplinary renal services team includes: 148 nurses and healthcare assistants, 12 nephrology consultants, a renal research team, a dedicated renal dietitian and pharmacy team, two social workers and a clinical psychologist.

The department provides care for adults with renal disease from their first referral and throughout their renal journey. Nephrologist-led outpatient clinics review individuals at all stages of renal failure. Clinical nurse specialist-led clinics provide information and education to individuals reaching end stage renal failure (who will require treatment to maintain life), allowing them to make an informed treatment decision. Treatment options will vary depending on individual circumstances but include:

- **Haemodialysis**: where individuals have hospital-based dialysis three times weekly, for four hours each time
- **Peritoneal dialysis**: where individuals self-care at home either intermittently during the day or overnight
- **Home haemodialysis**: where individuals self-care and dialyse 4-5 times per week for varying lengths of time
- **Kidney transplantation**: can be planned from a living donor and/or service users can go onto the waiting list for a cadaveric donor
- **Conservative management**: an active care package for those deciding against dialysis interventions

The nephrology ward provides care for those individuals requiring in-patient care for their kidney disease. The Department of Health policy document: *Supporting People with Long-term Conditions: An NHS and Social Care Model* (2005a) developed a three tier model to outline the support required by people living with long-term conditions. The Level One, support for self-care stage, applies to 70-80% of the chronic disease population. This is particularly important in the renal population. Renal patients may experience any or all of the levels represented in the Social Care Model during their renal journey progression, however, the vast majority of renal patients epitomise the Level One tier of the model. The supportive and self-care ideology could be reinforced with a peer support programme. Additionally, the second part of the *National Service Framework for Renal Services* (Department of Health, 2005b) identifies a generic standard for a patient-centred service, applicable to all patients with chronic renal failure. Part Two: Standard One identifies that:

> “Access to information that enables them [patients] with their carers to make informed decisions and encourages partnership in decision-making, with an agreed care plan that supports them in managing their condition to achieve the best possible quality of life”

(Department of Health, 2005b p 8).

The extended use of peer support would provide an important adjunct to the existing provision of care. This philosophy also feeds into the Department of Health white paper: *Caring For Our Future: Reforming Care and Support* (HM Government, 2012). The paper highlights the need to focus on carers
as well as individuals with long-term conditions. The support provided by carers and family is often underestimated but pivotal for those coping with renal disease. A peer support programme that can help to address the needs of these service users and their carers and family will help to embed the philosophy of patient-centred support (McCarthy, 2015).

**Project Aim**
To increase the range of person-centered support available to service users within University Hospitals Coventry and Warwickshire NHS Trust (UHCW) by developing a diverse peer support programme.

**Methodology: Participant Action Research**
The participatory nature of this form of action research provides the opportunity for individuals to identify issues within their own communities and facilitate change. Common features at the core of all action research approaches are concerned with action to develop practices, within a social setting. To provide pre-dialysis education presented by multidisciplinary healthcare professionals to a diverse range of pre-dialysis patients required action to be taken within renal services context to modify information delivery. The result is an interventionist, enquiry-based approach to achieving change, which is reflective and collective in nature (Vezzosi, 2006).

Additionally, the use of a cyclical research process emphasises the on-going reflection and evaluation of the situation under change and avoids development of a blame culture, if change is unsuccessful (Reason and Bradbury, 2008). The threat of retribution for unsuccessful change needs to be removed from the process if individuals are to engage honestly and openly with the research process. Constituents of the basic participatory action research steps are: a review of current practice; identification of an aspect to be investigated; imagining a way forward; trying it out; and taking stock of what happened (McNiff, 2002). Based on these findings the process continues in a cyclical form by: reflecting; planning; acting; and observing (Lewin, 1946).

The cyclical nature of action research aimed to allow the knowledge and skills that pre-dialysis educators need to emerge, so indicating where gaps between theory and practice exist. Participant action research aims to implement small changes, these can then be evaluated from a service provision perspective. However, it is important to note studies of less than 12 months’ duration have been shown to be less successful in their implementation (Titchen and Binnie, 1993).

Furthermore, those individuals involved with the action research will hopefully be influenced by their experience and take learning, and especially the reflective practice, back into their own sphere of learning. With evaluation and effective dissemination there is a potential to reach the wider nephrology community locally, nationally and internationally.

**Collaborative Participant Action Research (PAR) Meetings**
*What:* A multidisciplinary and service user group was developed through invitation to participate. The group included: The renal advanced nurse specialist (ANS); the renal psychologist; a renal dietitian; a renal nurse researcher; a transplanted patient; a haemodialysis patient; and a carer. Six 2-hour PAR meetings were held over an 18-month period, with ad-hoc additional meetings convened as required.
Why: A PAR methodology was employed to unite diverse stakeholders in a common endeavor to improve peer support for patients and carers. Individual participant expertise contributes to PAR through diverse understanding of pre-dialysis care and the integration of wide-ranging knowledge and experience.

How: Participants were invited from members of the multi-disciplinary renal team already involved in the education of pre-dialysis and dialysis patients, where peer supporter was being informally utilised. Recruitment focused on individuals who were experienced and had expertise in the field of renal patient education. Representation from the patient population was of paramount importance within the collaborative group. Diverse patient experience was sought in the individuals consenting to collaborate.

Data Collection
Literature review findings were presented to the collaboration and their implications for peer support development discussed.

A review of the renal and long-term condition self-management literature identified effective components in self-management education that support service-user decision-making. Self-efficacy theory (Bandura, 1977) was predominant in the literature and underpinned the development of self-management interventions (Morton, 2010b). The use of lay educators has also been shown to improve self-efficacy levels beyond healthcare professional delivery (Berzins, 2009). Additionally, peer support provides realistic practical information about the lived experience and is helpful in decision-making (Morton, 2010a; 2010b; Hughes, 2009). Guidelines recommend that the education of renal patients should be individualized, with high quality information, to facilitate informed treatment decision-making (Department of Health, 2005b).

Participant action research meetings provided a forum allowing individual experiences of peer support to be described and qualified. These could then be interpreted within the context of use and application.

PAR provided a range of data collection opportunities including:
- PAR meeting minutes and any documentation produced within meetings such as flip charts
- One-to-one meetings between participants and the researcher facilitator
- Reflective and reflexive diary kept by the researcher facilitator, including feedback from individuals

Data Analysis
Data collection and data analysis are discrete elements of the on-going reflecting, planning, acting and observing cyclical action research process. Systematic data collection, throughout the PAR ensured any peer support developments could be tracked and a decision trail created so that key decision points in the process could be identified, evidenced and if required revisited. Outputs created during the meetings and personal notes made during group reflections were reflected on as they related to group dynamics and non-verbal cues, as these were more difficult to convey in transcription.
Ethical Approval
A number of ethical considerations were examined during the proposal stage. The moral acceptability and the ethical dilemma raised in seeking help with a research programme, from those living in adverse conditions has been questioned (Oliver, 2003). However, one could argue that without such insight, as defined by those affected, patients’ needs may not be understood and met. PAR is therefore concerned with the realities of others and the power to frame their reality (Chambers, 2008) by hearing their voices and democratising research. The challenge lay in achieving a balance in the way participant influence was exercised (McNiff and Whitehead, 2006). When all parties bring knowledge, be it academic or experiential, to action research and all are perceived and acknowledged as knowledgeable in their own right, then power sharing occurs (McNiff and Whitehead, 2006). This is really important for creating an empowering environment and the impact collaborators can have on the wider renal environment.

As the PAR facilitator it was important to remain mindful that coercion at any point in the research process had the potential to compromise the welfare ideal. Coercion may sound a blatant and obvious activity, when in reality it may be far more subtle and insidious. Continual cognizance of power and privilege in working relationships was crucial. However, there is a fine line between the protection and empowerment of research participants (Bryden-Miller and Greenwood, 2006).

Confidentiality was paramount and group ground rules were agreed. Dissemination of any information that could identify individuals required consent prior to use. All data was kept on a password protected computer and paperwork in a locked cupboard in the researchers office.

Peer Support Training Days
What: Peer support training utilizing a training programme developed by NHS Kidney Care in 2013, unfortunately this online site is no longer available. Eight peer supporters were trained as the first steps of the action plan as devised by the PAR collaboration and a further four a few months later.

Why: Peer support training provides the opportunity to increase the diversity of experience offered by the peer supporters and increase the utilization of peer support. The use of lay educators has also been shown to improve self-efficacy levels beyond healthcare professional delivery (Berzins, 2009). Additionally, peer support provides realistic practical information about the lived experience and is helpful in decision-making (Morton, 2010a; 2010b; Hughes, 2009).

How: The training package was adapted to suit the UHCW context. A single day of training, rather than two sessions, was settled upon as accessing the site can be difficult, finding a parking space a struggle and the cost of parking prohibitive (though parking and travel costs were covered by the FoNS funding). Catering and refreshments were provided for the day. The training programme was delivered by the ANP and researcher, in the renal department’s seminar room. Volunteer services supported the day by being available to register individuals as hospitals volunteers. This included a Disclosure and Baring Service (DBS) check for criminal record, confidentiality information agreement and most importantly as registered volunteers, individuals were acknowledged for their contribution, could claim travel and parking costs, received a discount in hospital outlets and were invited to volunteer events.
Evaluation of Peer Support Training

**What:** At the end of the peer support training, participants were asked to complete an evaluation form. Additionally, the PAR group completed a group reflection on the collaboration experience.

**Why:** Evaluation and reflection provided the opportunity to stop and take stock of progress, the process of getting there and review any elements that could be improved.

- Feedback suggested that some individuals were unsure of what to expect of the training and therefore whether they had learned what they had hoped to
- Participants agreed or strongly agreed that the training was clear and easy to follow, it was interesting, improved their skills for supporting kidney patients and carers
- In relation to the trainers, participants agreed or strongly agreed that useful real examples were given, feedback was useful and individuals all felt they were involved in activities and discussions
- The overall feelings about the training day reflect that the pace and length of the training were appropriate, timing was convenient and the day was rated as good or very good by all participants
- The scenario and discussion format was interesting, engaging and included diverse opinions and discussions
- Participants identified that it would have been good to talk to existing peer supports
- The provision of refreshments and lunch was appreciated and made the day more sociable and relaxed

**How:** Written feedback on evaluation form supplied with the training package was collected from all peer supporters trained. This included open questions that were analysed by the researcher. Group reflection was used in PAR meetings, along with the meeting minutes and any documentation produced during the course of the meeting. Reflections that were developed were shared with the PAR collaborative group to ensure accurate and trustworthy analysis.

Dissemination

**What:** Dissemination of the project to staff and service users.

**Why:** Peer support relies on individuals being referred to the service or self-referring to initiate contact. It was important for staff and service users to be aware that the service was available, what it was for and how to contact the peer support team.

**How:** The peer support project was disseminated at multidisciplinary forum meetings. An information flyer was created and emailed to all renal services staff. Flyers were posted in staff areas. Full sized posters were developed and located in patient waiting areas and education facilities. An article was written by one of the service users and published in the local Kidney Kourier a Kidney Patient Association (KPA) magazine. The researcher presented to the local KPA and patient forum.

Claims, Concerns and Issues

**What:** Claims, Concerns and Issues (CCIs) (Guba and Lincoln, 1989) was the method used to gain the
views and perspectives of individuals about peer support and referral to peer support.

Why: Despite attempts to disseminate information about peer support, the number of referrals to the service remained minimal. Specifically, the nephrology consultants failed to refer any patients to the service. To understand better the issue a meeting using the ‘Claims, Concerns and Issues’ (CCI) method was used.

How: Using the classic three heading flip-chart, individual claims, starting with “I believe…” were recorded, concerns documented and the over-riding issues extracted. The main concern was a lack of understanding about the selection and training of individuals and the fear that they would provide erroneous information. The researcher and ANP were able to explain the training and selection process, the boundaries of the role and the benefits to patients receiving peer support.

Challenges/Barriers
Collaboration Challenges: Challenges within a collaboration require different skills in the action research facilitator. Keeping the action research process on course required varying degrees of micro and macro level input as issues arose. Reflexivity enabled the researcher to be aware of their influence, upon the research process, gained through critical self-awareness. The on-going process of critical self-awareness makes explicit the influence of the researcher on the research, and conversely the influence of the research on the researcher (McCarthy, 2014). As a central concept in qualitative research, reflexivity adds credibility (Dowling, 2006). By maintaining a reflective and reflexive diary the facilitator will make the research process transparent and aims to add rigour to the qualitative research.

Cultural Challenges: Traditionally within the NHS, value is placed on evidence-based practice, acquired through academic knowledge and understanding. Challenging this concept in the wider renal service community and embracing experiential knowledge went against convention. Prior successful action research within the department helped to establish the benefits of participant involvement within the renal services. On-going and regular presentations and up-dates of the project to the renal multidisciplinary service audience aimed to keep staff abreast of peer support developments and to challenge established practice. The selection of peer supporters and their training was well planned and straightforward. Training evaluated well and peer supporters were keen to put their learning into practice. A greater diversity of peer support experience was achieved, with all treatment experiences covered, an improved age range from 40s-70s covered, gender and carer representatives. Thus, it would appear that we had achieved our aim. However, peer support is only effective if: a) referrals are made, b) when they are made, peer supporters respond and c) there are sufficient staff to facilitate coordination of peer support. These three issues will be explored in turn.

a) Referrals: Initially the advanced nurse practitioner team was the only HCPs referring to peer support. There were a couple of staff consistently utilising peer support and this was most pronounced in the acute start patients; individuals who were unaware of their renal failure and had no preparation time before they require dialysis treatment to keep them alive. One peer supporter, who had commenced dialysis as an acute starter, was particularly good with these new patients as one patient reflected “It gives you hope that everything might be ok, when you’ve seen someone who’s been through the same sort of thing”. Following the CCI session there were referrals from
four of the nine consultants, the hope being that as patients reported back their experience of peer support, consultants’ confidence in the service would grow and encourage further use. However, two concurrent issues arose resulting in a decrease in uptake. These are discussed in greater detail below.

b) Peer Supporter Response: Peer supporters were warned that it might take time for their services to be called upon. This had been found in other peer support programmes, set up in another local trust and shared at Peer Support Networking meetings. What we found was that in reality, five of the ten peer supporters were regularly engaged and the others were unavailable or unreliable. Those regularly engaged supported the acute start patients, the pre-dialysis education day at the main unit and the education day at a satellite unit, and one individual selected only to support South Asian patients. Despite a preference form being completed during the training day it was only once supporters started, that their preferences became evident, to themselves and to us. This left gaps that we had initially thought we had covered. Also half of the peer supporters trained, when they were asked to support someone were unavailable or failed to respond to requests. The nature of renal failure resulted in two patients being transplanted and returning to work so not being available; the acute start peer supporter’s partner became unwell requiring full time care; and for others, their fluctuating levels of wellness impacted on their availability.

c) Sufficient staff to facilitate coordination: Ultimately, an extensive critically low level of staffing resulted in the ANP facilitator struggling to maintain her caseload of patients and leaving no time to chase up peer support issues and develop new peer supporters.

Current Situation
A core of four peer supporters continues to attend the main unit and satellite unit information days for pre-dialysis patients. A further peer supporter is a co-applicant on a funded research study. However, referrals from consultants have ceased and the lack of trained peer supporters has resulted in the use of untrained peer support. The ANPs are able to use untrained peer supporters because they knew the patients and could identify appropriate patients and engage them. Having interviewed patients who have received such untrained support, as part of another funded research study, they reflect on the reality and truth they got from someone who has experienced treatment first hand. Though patients rate the nursing staff highly and the education they provide, they are unable to provide the lived experience.

Peer Support at a National Level
The project lead was invited to join an NHS England and Renal Registry work programme entitled ‘Transforming Participation in Chronic Kidney Disease’ 2014-2017, on the basis of her PhD research and peer support involvement. Hence, the learning from the experience at UHCW, which is reflected nationally (Hughes, 2009; Wood, 2015), has been taken to a level of national interest and she continues to work collaboratively to address peer support issues through the practical experience gained. Furthermore, UHCW is one of two pilot sites nationally for trialing self-care interventions recommended by NHS England and this will include peer support.

Discussions around peer support within the department and at a national level have identified a
number of considerations:

- Focusing on patients who regularly provide peer support and only training them once they have established a commitment
- Seeking wider input at the start of any introduction/re-introduction of peer support to ensure all staff groups have link people that can feedback developments
- Identifying patients for specific peer support roles i.e. acute starts, information days etc. and linking them directly with the HCP responsible for the event. This would aim to increase ownership and communication between staff and peer supporters
- Potentially, train a patient to deliver peer support training to counteract the high turnover of supporters for a multitude of reasons and lack of HCP time
- Continue to collaborate with renal specialists nationally with an interest in peer support, through NHS England to push the agenda forward
- Seeks financial support from charity funding to employ a patient to coordinate a peer support programme

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