

What happens when you involve patients as experts? a participatory action research project at a renal failure unit

Kerstin Blomqvist,^a Eva Theander,^b Inger Mowide^b and Veronica Larsson^b

^aKristianstad University College, Kristianstad, Sweden, ^bHässleholm Hospital, Hässleholm, Sweden

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Although there is a trend towards developing health care in a patient-centred direction, changes are usually planned by the professionals without involving the patients. This paper presents an ongoing participatory action research project where patients with chronic renal failure, nurses at a specialist renal failure unit, a hospital manager and a researcher worked together to develop patient-centred care. The project combined the expertise of patients in their own experiences of living with a chronic condition with the professional expertise of nurses, the manager and the researcher. As the workload on the unit was uneven, the development work needed to be low in intensity but long-term. Based on a number of dialogues in focus groups, four main development areas were identified; access to test results, prerequisites for postponing the progress of the illness, general awareness and understanding of living with chronic renal failure, and family-focused care. A number of changes have been planned or implemented, such as developing a prototype for a web-based feed-back system, expanding patient education to newly diagnosed patients, steering the nurses' role towards a guiding and family-focused function, and planning a digital story-telling workshop. Involving committed people who have the mandate to change practices were prerequisites for success.

Key words: chronic renal failure, participatory action research, patient-centredness, patient education, self-care.

Patient-centredness is a slowly developing trend in health-care. The term patient-centredness was introduced by Balint (1996) as a way to understand patients from an everyday life perspective, as well as to give patients more control over their life situation. From a professional perspective, patient-centredness builds on the desire to understand the patients' needs and wishes, a willingness to share knowledge and power, to involve patients in the decision-making, and to ask for the patients' views on their condition (Mead and Bower 2000). There is an expectation that patient-centredness will increase the patient's own activity and responsibility in relation to his/her own illness and thereby contribute to better health and life satisfaction. It also replaces a view of patients

as passive receivers of the actions and prescriptions that medical professionals have ordered in their expert roles. The trend can be seen as an endeavour to reach a more humane position (Wackerhausen 2002) where patients have the freedom both to make their own choices and to be more closely involved in their own treatment. Expert patient and patient participation are other concepts that have recently become more common in health-care and nursing (Cahill 1998; Collins 2007; Eldh, Ekman, and Ehnfors 2008). Expert patients have received their knowledge about their illness and treatment from the professionals, and also from self-learning. In one sense, all patients are experts, as nobody else knows their body and their living environment better than they themselves.

Although patient-centredness is applicable to a wide range of conditions, it may be of the greatest importance for chronic or long-term illnesses. This study focuses on chronic

Correspondence: Kerstin Blomqvist, RN, PhD, Senior Lecturer, School of Health and Society, Kristianstad University College, SE-291 88 Kristianstad, Sweden.
E-mail: <kerstin.blomqvist@hkr.se>

renal failure care as this condition often dramatically influences both the patients (Bass et al. 1999; Heiwe, Clyne, and Dahlgren 2003) and their families (White et al. 2004; Low et al. 2008). Previous qualitative research has shown how patients experience that their illness affects them physically with, for example, tiredness (Bass et al. 1999; Ravenscroft 2005) and pain (Ashby et al. 2005), and also mentally with anxiety (Bass et al. 1999), low endurance (Bass et al. 1999; Ravenscroft 2005) and self-guilt (Ravenscroft 2005). Lifestyle restrictions due to the illness sometimes make it hard to balance between illness and normality (Krespi et al. 2004; Ravenscroft 2005). Lacking energy to perform household chores (King et al. 2002; Heiwe, Clyne, and Dahlgren 2003) or to work full-time (King et al. 2002) affects both the person with chronic renal failure but also his/her family. The illness and its treatment affect the social relations and role functions (Bass et al. 1999) and create a fear of being a burden to the family (King et al. 2002; Caress, Luker, and Owens 2008). As the illness is progressive, it evokes existential thoughts about life and death (King et al. 2002; Hagren et al. 2005; Ravenscroft 2005; Caress, Luker, and Owens 2008). How each person with chronic renal failure reacts to the situation differs, however (King et al. 2002; Caress, Luker, and Owens 2008). Although some patients view the illness mainly as an enemy or a loss (Caress, Luker, and Owens 2008), others react by looking back at and longing for their previous life (Ashby et al. 2005; Hagren et al. 2005) or looking forward and view the illness as an incentive to make the most out of his/her life (King et al. 2002; Caress, Luker, and Owens 2008). With this picture in mind, it seems evident that chronic renal failure, like most other serious chronic conditions, causes major changes to the patient's everyday life.

Recently, questions about utility have raised increased interest in healthcare research (Chesla 2008). Participatory action research (PAR) is said to be a style of research that is well suited to solving problems in practice (Meyer 2000; Stringer and Genat 2004). To reach utility and to bridge the gap between theory and praxis, PAR includes stakeholders in the entire research process, from defining the research question to implementation and evaluation. Also, the quality of a PAR study is judged in relation to its usefulness in practice. Although a number of research studies have examined concepts such as patient participation (Cahill 1998; Collins 2007; Eldh, Ekman, and Ehnfors 2008), studies on how to create patient participation in practice are rare, indicating that the utility of research is complex and often difficult to achieve. This PAR study aimed to explore what improvements patients with chronic renal failure asked for at a specialist clinic, and to use their expertise as a tool to develop patient-centred care.

THE DEVELOPMENT OF THE PROJECT

The project had its starting point in a huge regional development work in Southern Sweden, Skåne's *Life force, care and health* (1999). The three overall aims of that work were to increase the accessibility to health-care and social care, to improve the collaboration between providers and organisations, and to make health-care more participatory and in line with the patients' needs and wishes. Although patient participation was one of the main issues, most of the actual local development work had started from a healthcare provider and/or managerial perspective. Yet without patient involvement in the development work, their opinions would not be taken into account.

A central methodological issue in PAR is participation, which means to include not only researchers but also other people concerned with the issue at stake (Meyer 2000). The staff at the renal failure unit were asked to raise ideas for research about patient participation. They were requested to reflect on and answer the question: What do you want to know from your patients that only they can tell you? The main issues raised involved two areas. One was about the treatment. Questions in this area revolved around how the patients experienced the staff at the unit and the medical treatment, and how they viewed participation and involvement in their own care, and treatment and the environment at the unit. The other area involved issues about the daily life of a person with chronic renal failure. Questions in this area revolved around how patients experienced their everyday life with renal failure, as well as their concern about their medical condition. Inspired by Sarv (2006), who uses the metaphor of a Formula One race to express the role of health-care in people's lives by comparing the pit stop with the health-care and the race with the patients' everyday life, we asked ourselves how the renal failure unit (the pit stop) could be developed to improve the everyday life of patients with chronic renal failure (the race).

For practical reasons, the project was organised as a core group with staff and an outer group with co-researching expert patients. The core group included two nurses from the renal failure unit who initially had expressed great interest in developing more patient-centred care in the unit, a researcher working in a PAR unit at the nearby university and the head of the development unit at the hospital. The nurses had great experience from a variety of renal failure treatments and worked on a specialist ward. They met patients with chronic renal failure in early as well as late, pre-dialysis phases of the illness. As they were responsible for preparing patients for a possible future transplantation or dialysis, educational matters were of great interest. The outer

research group included four patients with chronic renal failure who had responded positively to an invitation to participate in focus groups as expert patients. The invitation was sent to 19 persons in the pre-dialysis phase (i.e. glomerular filtration rate <25 ml/min). Six people expressed an interest, but only four showed up at the first meeting. These four, two women and two men aged between 40 and 80, became the co-researching expert patients in the outer group. In addition, the project reported to and interacted with the managers at the unit, as well as with a number of professionals such as dieticians, nurses, physiotherapists and social workers.

The core group decided to start to explore issues that concerned the daily life of a person with renal failure and how to develop a supportive unit. To clarify pre-understandings about the issue at stake, members of the core group met and discussed their understanding of patients with renal failure, such as how patients experienced coming to the unit and what they thought about the patients' experiences and wishes. The expert patients in the outer group were then invited to a number of focus group meetings. The invitation letter informed the patients that the meetings should deal with two main issues, how the illness had influenced their entire life situation and how they wanted to influence their situation at the unit. These two issues were used as prompt guides during the discussion at the first focus group meeting. The meetings took place over a period of 1.5 years. The meetings aimed to clarify if the work at the unit was in accordance with the views and needs of the expert patients and, if not, to plan for changes.

Before the project started, the core group had a discussion about ethical issues and identified a number of issues to consider based on the literature on ethical issues in PAR: fair subject selection, informed consent and a favourable risk-benefit ratio (Khanlou and Peter 2005). The initial discussions revolved around the possible consequences of turning to patients considered as eloquent and willing to discuss. The risk that their views and wishes would differ from those of more disabled or reserved patients led to a decision to invite all patients except those with dementia and the most severely ill. As previous research has pointed out the unwillingness of people who are at an early phase of a chronic life-threatening illness to meet people in late phases (Sandaunet 2007), the members of the core group decided to start with a homogenous group of patients at about the same phase of the illness, that is, the pre-renal phase. Also, a self-reflection and training session was held on how to handle difficult situations that could come up and how to make the focus group discussion a dialogue. The information and consent letter developed by the core group included a question about tape recorder use. As one of the expert patients expressed unwill-

ingness to have the focus group dialogues recorded, written notes were taken by two people in parallel throughout the entire project. These notes were analysed for content by the core group. To make sure that there was an agreement about the analysis, a number of member checks (Stringer and Genat 2004) were carried out in the entire group. Ethical issues were discussed in the hospital's local ethical committee, which approved of performing focus group meetings with one group of expert patients.

FINDINGS AND PLANS FOR THE FUTURE

The focus group discussions showed that the expert patients were satisfied with most of the care, but revealed four areas that needed to be developed: to provide access to test results, timing of the receipt of information about the progress of the illness, to increase the awareness and understanding in society of the daily life challenges people with chronic renal failure have to tackle, and to involve their families.

Access to test results

The expert patients highlighted the importance of having access to test results, not only when the condition had worsened, but also when results were stable. This information was important for their everyday well-being.

I have gotten used to that you [the nurses] contact me if something is wrong. Not everyone does that, but it should be mandatory. One becomes twice as happy if the test is ok. It is important to know when it is a little better.

By connecting with the information and communication technology department of the university and a new group of patients at an early phase of chronic renal failure, a first prototype of a web-based feedback system has been developed.

Timing of the receipt of information

Although the members of the inner group were well aware that tiredness is a common problem for patients with renal failure, none of the expert patients had understood the connection between tiredness and chronic renal failure. Instead, they linked tiredness to their age or to being lazy. This made us realise that prior to giving information the nurses needed to explore the patient's learning needs by asking them about their beliefs and questions. The need for nurses to consider the timing in the patient education was another issue brought up in statements such as 'Not too early and not too late'. This is expressed in the following quote:

Information about the disease could be given early on. It gives an understanding when there are changes in the condition. At that time, you also want to know about self-care. But not too early. I've been here for 15 years. If I had gotten information at that time, I might have brooded more, maybe too much. It is very individual when you want to know.

Information about what could be done to delay the development of the illness was central at an early phase of the chronic renal failure. Later, information on treatment such as dialysis should be provided to enable the patient to participate in decisions about treatment.

Patient education is now expanded to newly diagnosed patients with high blood pressure and leakage of protein, but who are not feeling sick. A more flexible system for patient education, where patients are allowed to come when they feel 'ready' to learn more, is also being tried. The content of the sessions has changed from focusing mainly on the medical condition towards issues related to healthy ways of living with the illness and what can be done to delay its development. The structure of the sessions has changed from lectures towards learning and understanding in group discussions based on questions from the group. A new feature is, for example, 'Ask the Doctor'. This part of the project is subject to formative evaluation, and the structure and content of the sessions are continuously changed.

Awareness and understanding

Although the expert patients themselves often knew, for example, what food they should avoid, attitudes of family members or friends sometimes made them feel like whiners. They expressed a need to increase general awareness of renal failure and how the condition affects their everyday life.

My husband does not accept it. That is the problem. I think it would be good if he knew more, but he does not want to know. He is in denial.

It is a struggle for me, too, to make the family members understand.

There are those who envy me since I get a pension, without working.

The entire group discussed how to tackle this issue and spoke about information folders but no one felt convinced that folders would be a proper solution to the problem. During this project, the researcher in another project learned about a method called digital storytelling (Wyatt and Hauenstein 2008). This method has been used as a tool to share stories about values and attitudes. A future project activity

will be to invite patients with chronic renal failure to produce their own digital stories about a life with chronic renal failure and try to use the stories to influence attitudes.

Family focus

The belief of the core group was initially that the illness affected the entire family, and we spoke about the patient as being a burden to the family. The expert patients made us realise that the burden was not one-sided, as all of them simultaneously acted as caregivers for family members and received support from the family. A large part of their worries concerned how their family would manage when the illness progressed. This is an illustrative quote from one of the expert patients:

I have to look after my wife, she cannot manage on her own. She cannot get out of bed.

This insight became the starting point for a drastic change in the education program. One aspect of this was to invite the entire family to the learning sessions and to provide more time for group discussions about issues of concern, to both the patients, and to the family members. In addition, patients with experience of institutional dialysis, dialysis in the home and living with a kidney transplant, as well as their partners, are involved in the education.

DISCUSSION

This study aimed to investigate what improvements patients with chronic renal failure at a specialist clinic asked for, and to use their expertise as a tool for developing patient-centred care. Four areas that needed to be improved were identified, access to test results, timing of the receipt of information, increased awareness and understanding in society of the daily life challenges that people with chronic renal failure have to tackle, as well as family involvement. One question that needs to be asked is what contribution the expert persons gave, and if they acted as patient experts. With the wisdom of hindsight, we can see that none of the development areas were totally new to the members in the core group, but their understanding differed somewhat from that of the expert patients. Two of these areas involved patient education, an activity that the two nurses had been deeply involved in for a long time. The expert patients helped the core group members see and differentiate information that should be provided in the early and late phases of the condition, respectively. The term *timing* also made it clear that invitations to participate in patient education at predetermined times was not optimal. 'It became a revolu-

tion in my head' was a statement from one of the nurses when it suddenly dawned on her that education needs to consider timing, that is, it needs to be available when the person feels a need for it. As timing still constitutes a problem and a challenge for the nurses who are responsible for patient education, more research into the 'timing' issue is urgently needed.

Access to results from blood tests was another area for development that did not surprise the core group members who were aware that patients need to know when something is wrong and needs to be acted upon. What the expert patients made us understand was that, from an everyday perspective, patients want to know when tests are stable, as this brings well-being and may act as an indicator that their self-care activities are paying off. The lack of awareness on the part of the core group may be a result of the biomedical model of illness that has dominated the healthcare sector for the past century (Wade and Halligan 2004), that is, that what matters is that medical problems are identified and solved. Abma, Nierse, and Widdershoven (2009) noticed, however, that blood tests are means for the patients to interpret and understand not only the illness as such but also the well-being and health aspects.

The development area that surprised the members of the core group the most was that the chronic renal failure patients often were main caregivers for family members. Thus, the image of the chronic renal failure patient as just a 'burden' to the family needs to be altered. The issue of interdependency was not discussed in-depth until the third group meeting. When it came up, all the expert patients indicated strongly the importance of the interdependency situation. This finding is similar to what Nolan, Keady, and Grant (1995) have pointed out in their study about family members of persons with dementia. Until recently, it has been taken for granted that the family members who act as caregivers see the person with the illness as a burden. Their study point out that this is not the full picture, as care-giving also gives the caregiver a sense of satisfaction. Our study contributes with insights that the patient is often both the person cared for and the caregiver to a family member. The concept of interdependency needs to be highlighted and reflected upon among healthcare professionals.

Methodological discussion

Participatory action research is not a uniform scientific tradition. One tradition is the pragmatic and another is the emancipatory (Lundberg and Starrin 2001). The pragmatic approach is based on an idea that involving people in the research process will make them motivated to work for

change in practice, while the idea behind the emancipatory approach is that the research should empower people by making them aware of their own situation and of existing inequality. Although this was never clarified at the beginning of the project, our initial discussions about patients as experts indicate that we adhered to the emancipatory movement. The project went some way to reaching the situation described by Abma, Nierse, and Widdershoven (2009) where 'he [the patient research partner] is involved with researchers in a mutual learning process that changes both parties' (404). The members of the core group noticed a shift in their own way of thinking about patients, and in the actions of the expert patients. This was interpreted as an indicator of empowerment. Despite this, the expert patients may not have reached what Sandaunet (2007) describes in a study of participation as 'a sense of fitting in'. The meetings in the core group were open, and knowledge, ideas and opinions were exchanged freely. The same openness was never reached when the members of the core group met the expert patients. This may have been caused by the meeting environment and the way we worked, that is, the members of the core group met to analyse, reflect upon and plan coming changes based on focus group meetings at the renal failure unit together with the expert patients. As the expert patients were patients at this unit, they may have felt like patients also in the project. Bearing this in mind, the suggestion from Abma, Nierse, and Widdershoven (2009) to start the development work with the stakeholder group of least influence, that is, the patients, needs to be considered in future steps of this project.

This project was in intensity but long-term. During the project, the members of the core group have been aware that the prolonged process may be a negative factor, as the expert patients are suffering from a progressive illness and might be unable to participate throughout the project. The core group members also saw a risk that the financing bodies may withdraw their support if the project did not deliver results. However, based on experience from previous action research projects (Petersson, Springett, and Blomqvist 2009a, 2009b) the core group decided to involve everyone at all stages in all aspects because we were convinced that this would maximize the possibilities to reach sustainable change. As the nurses had to do all the development work as part of their daily tasks at the unit, and as they were overburdened with work from time to time, the project needed to be planned around the nurses' workload.

The role of the university researcher became what Stoecker (1999) calls a collaborator. Stoecker describes the different roles of the action researcher, as an initiator, a consultant or a collaborator. She suggests the collaborator's

role as the one with the best possibility to reach sustainable change. By planning and working together within the core group and with the outer group, and by adapting the project to a continuously changing everyday reality, the intention was to do something that led to a sustainable change in practice. After almost 2 years of work, experience indicates that had the project been designed as a traditional research project—that is, planned in detail from the very beginning—sustainable change in practice would not have eventuated.

One risk with this project relates to the fact that it involved only part of the renal failure unit. During the project, the core group members realised the significance of the fact that the renal unit work acted as three more or less separate parts (the renal failure specialist ward, the peritoneal-dialysis ward and the hemodialysis section) and not as a whole unit. Apart from the four identified development areas, an overriding question remains to be solved, that is, how to involve the peritoneal dialysis and the haemodialysis sections in a patient-centred work method.

In summary, running the project on a long-term and low intensity basis, as well as involving people who were deeply committed, felt responsible and had a mandate to make changes that were prerequisites for the project. Although the project did not fully succeed in working in the emancipatory tradition of PAR, the expert patients in the outer group and the members of the core group all contributed and made a difference. Everyone working together discovered issues that could be changed, whereas the members of the core group assumed the responsibility to implement the changes and write the report.

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