

The Impact of a Nurse-Led Clinic on Self-Care Ability, Disease Specific Knowledge, and Home Dialysis Modality

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Chronic kidney disease (CKD) infringes on life and often leads to significant functional impairment. One goal for nursing care is to improve the patient's quality of life during every stage of the disease. Factors such as late referral to specialist care, inadequate care during the early stages of CKD, symptoms, and physical, psychological, and social effects of the disease affect how these patients perceive their quality of life (National Kidney Foundation [NKF], 2000). In Sweden, the care of people with CKD is based to a large extent on patient participation and it is carried out mainly at home, either by the patient or by relatives. Patient education is therefore an important part of the treatment.

Several studies on the impact of early education for patients with CKD show positive effects such as delayed initiation of renal replacement therapy (RRT) (Devins, Mendelssohn, Barre, & Binik, 2003), increasing proportion of permanent vascular access (Lindberg et al., 2005), more patients intending to and starting dialysis with a self-care modality (Goovaerts, Jadoul, & Goffin, 2005; Manns et al., 2005), and extended survival (Devins, Mendelssohn, Barre, & Binik, 2005). The care goals are thus to support

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A nurse-led clinic focusing on education and self-care for patients with advanced renal failure was introduced in a renal outpatient clinic in Sweden. The purpose was to enhance the patients' disease-related knowledge, involvement, and self-care ability. This article reports the results of a study comparing patient outcomes with the nurse-led clinic to the previous model of care. The hypothesis was that the nurse-led clinic would increase medical control and self-care outcomes. The participants in the nurse-led clinic chose and started dialysis in a self-care alternative and also had a functioning, permanent dialysis access to a greater extent than the patients in the comparison group. Those choosing home-hemodialysis rated their self-care ability higher. The participants rated self-care and effects of treatment options on family and everyday life as the most important disease-related areas of knowledge.

patients in handling their health-related situations and to empower patients to achieve a higher level of disease-related knowledge, capability, autonomy, and self-efficacy; and better control of their life situations. In summary, it is a question of supporting and increasing patient involvement and self-care ability. Involvement means understanding and having knowledge about one's health-related situation, and being able to take part in plans and decisions concerning one's own care. In this context, self-care can be described as the activities required for an optimal daily life with a disease. Self-care ability can be briefly described as knowledge, competence, and activities related to health (Orem, 1985).

The specific components of self-care applicable to people with Stage 4 and Stage 5 CKD (i.e., with glomerular filtration rate (GFR) less than 30 ml/min) are having control over nutritional and fluid intake, physical activity and weight, as well as monitoring bodily signs and symptoms (e.g. shortness of breath, edema, nausea, pruritus, dizziness, and signs of infection). It may involve tasks such as maintaining a diet, blood pressure measurements, managing medication, dialysis access care, and, in cases

of diabetes, maintaining good metabolic control. When renal care is commenced at an early stage of CKD, the rate of reduction of renal function is slowed, and the need for the onset of RRT delayed (Nahas & Bello, 2005; Ruggenti, Schieppati, & Remuzzi, 2001), which is a significant gain, both from a patient and a public financial point of view. There is evidence showing that patients who are well controlled before the onset of dialysis do better when dialysis treatment is started (Jungers et al., 2001).

The overall goals in Sweden regarding the care of patients with advanced CKD – who can also be defined as high-risk patients – are to reduce progress of renal impairment; reduce complications of renal failure; reduce risk factors for later complications and mortality; prevent or alleviate uremic symptoms; prepare the patient, both physically and mentally, before dialysis or transplantation; and to offer good palliative care when RRT is not an option (SNF, 2007).

The prevalence of RRT is the prevalence of patients in HD, PD or kidney transplant in 2005. With approximately 9 million inhabitants – the total sum is 7377 patients – in Sweden in 2005 was 815 per million inhabitants and the incidence was 125

per million inhabitants Glomerulonephritis is the most common ESRD-causing disease among prevalent patients on RRT, and diabetes is the most common cause among incident patients. Among Swedish incident patients on dialysis, 72% started with hemodialysis (HD) and 28% started with peritoneal dialysis (PD) in 2005. Their mean age was 65 years. In Sweden, patients are usually referred to a nephrologist when the GFR is 40-50 ml/min or below. Care in a renal outpatient clinic usually includes visits to a physician with patient educational measures managed by nurses (i.e., information on RRT options individually and “kidney schools”). However, it is becoming more common to have additional nurse-led clinics to complement the renal physician care.

The renal outpatient clinic at the Karolinska University Hospital/Solna has a pool of approximately 200 patients with GFRs of less than 20 ml/min. The patients usually see their physician at the clinic 3-4 times per year. Our clinic is striving for a high degree of self-care treatment. We encourage our patients to choose self-care dialysis (i.e. PD, self-HD, or home HD) whenever appropriate, and to have a well-functioning, permanent dialysis access at least 3 months before initiation of dialysis.

Nurse-led Clinics: Previous Experiences

From an international perspective, the nurse-led clinic concept as a specific service has developed since the 1990s. Previous studies have shown the following effects of nurse-led clinics: lifestyle changes; increased prevention; fewer hospital admissions; an improvement in quality of life, disease-related knowledge, and self-care and compliance; and reduced waiting times and costs (Grady et al., 2000; Griffiths et al., 2004; Loftus & Weston, 2001). It has also been shown that nurse-led prevention clinics are effective in achieving risk factor targets (e.g. overweight, hypertension, serum lipids, smoking habits and

Table 1
Participants in Nurse-Led Clinic, Background Information

	Patients in nurse-led clinic	Comparison group
Patients, total number	70	153
Male	48 (69%)	100 (65%)
Female	22 (31%)	53 (35%)
Age (Mean)	67 (Range 36-89)	65 (Range 19-88)
Diabetes	22 (31%)	53 (35%)
Glomerular Filtration Rate (GFR), ml/min. (Mean)	13 (Range 5-30)	14 (Range 4-39)
S/Creatinine, μmol/L(Mean)	410 (Range 157-845)	384 (Range 130-953)

physical activity degree) (Denver, Barnard, Woolfson, & Earle, 2003; Mainie, Moore, Riddell, & Adgey, 2005; McHugh et al., 2001).

Despite our previous efforts to prepare patients for RRT and inform them about dialysis options, we found that the patients in our outpatient clinic experienced shortcomings related to information, conveyance of disease-related knowledge, overall view and involvement in care decisions (Picker Institute Europe, 2003). For people with chronic illnesses, these areas are important in terms of understanding their situations and coping with the self-care that is required.

The hypothesis of this study was that a nurse-led clinic, focusing on education and self-care, would be able to meet these reported shortcomings and further improve the opportunity for optimal care, and contribute towards increased involvement and self-care skills in patients with advanced renal failure.

Methodology

Design

This study was part of a clinical practice development project. Two nurses were engaged in the study. They each had 15-20 years of professional experience in renal care. Their educational levels were R.N, B.Sc. in Nursing and R.N, M.Sc. in Soc.Sc; Caring Education. They also had additional post basic education in motivational and cognitive patient

education. Alas Sweden does not have any certification or special training in nephrology nursing.

Participants

During the study period of 12 months in 2004, 70 participants were recruited to the nurse-led clinic. The participants had CKD in Stages 4-5, were not yet on RRT, and were being seen regularly by a physician in the outpatient clinic. The majority of the participants had a GFR of less than 20 ml/min (see Table 1). Participants were informed about the study verbally as well as in writing and enrolled on voluntary basis. They were referred consecutively by their physicians when the physicians decided that there was a need for increased self-care support, psychosocial support and/or medical control (i.e., blood-tests, blood pressure, symptom monitoring, nutritional status, postoperative check-ups etc.). At baseline, the participants’ mean S/Creatinine was 410 μmol/L and the mean estimated GFR was 13 ml/min (see Table 1).

The comparison group consisted of 153 patients with advanced renal failure, not yet on RRT, who had conventional care (see earlier description) without access to a nurse-led clinic in our unit during 2002 (see Table 1).

Procedure

Patient visits occurred at varying intervals, depending on the patients’ needs and wishes and on the rate of progression and symptoms of the

renal failure. The goal was that the patient would see the nurse and the physician on every other visit, respectively. The nurse gave feedback to the physician. Each visit to the nurse-led clinic lasted approximately 60 minutes. Our goal was to use motivational interviewing (Lange & Tigges, 2005; Miller & Rollnick, 2002; Shinitzky & Kub, 2001) using open-ended questions, maintaining an empathic attitude, avoiding argumentation, using active and reflective listening, and using timed exchange of information. The content of each visit was determined largely by each individual patient's questions and wishes. The focus was on discussions aimed at motivating, guiding, and supporting the patient, education (e.g., about kidney function, symptoms and common health problems related to renal failure, test results, effects of medication, treatment alternatives); self-care (e.g., diet, physical activity/exercise, medication, control of blood pressure and any occurring oedema); daily life with a chronic illness; well-being and quality of life; and health check-up (uremic symptoms, blood pressure, dialysis access function, test results, nutritional status, and SGA). The ASA questionnaire and a study-specific questionnaire to assess disease-related knowledge were used on the second visit. The participants were also given education material especially developed for this patient group in the form of a patient diary – "CKD Diary" (Melander, Pagels, Eriksson, Wång, & Magnusson, 2004). The diary provided an opportunity to read about different areas related to renal failure, and for the patients to make their own notes on health data, thoughts on health goals, behavioral changes, the disease, and one's own life situation. It was also used as a basis for discussion during the visit to the nurse clinic.

Questionnaires

The Appraisal of Self-Care Agency (ASA) questionnaire (Gast et al., 1989) is based on Orem's Self-Care Theory (Orem, 1985). The instrument contains components

Table 2
Choice and Initiation of Dialysis Mode in Nurse-Led Clinic

<i>Participants who had:</i>	Number (n) / total number (n)	%
Chosen a form of dialysis	61 / 70	87.1
Chosen self-care dialysis	36 / 61	59
Chosen conventional HD	22 / 61	36
Chosen to decline dialysis	3 / 61	4.9
Started dialysis	21 / 70	30
Started conventional HD	10 / 21	47.6
Started self-care dialysis	11 / 21	52.4
Started dialysis with permanent dialysis access	19 / 21	90.4

Table 3
Outcomes in Nurse-Led Clinic and Comparison Group

Outcomes	Patients in nurse-led clinic (N = 70)	Comparison group (N = 153)
Chosen self-care dialysis	59%	40%
Started self-care dialysis	52%	33%
Started dialysis with permanent dialysis access	90%	61%
Started dialysis with emergency dialysis access	10%	39%

which reflect motivation, as well as cognitive and cognitive aspects of self-care ability and is comprised of 24 questions. The responses reflect a subjective estimation of self-care ability and scores range from 24-120. A higher score indicates a higher estimated self-care ability.

Inspired by the Toronto Informational Needs Questionnaire (Galloway et al., 1997), a study-specific questionnaire about disease-related knowledge and educational/informational needs (KEQ) was created. The aim of the questionnaire was to establish what information the patient regarded as important and what areas of knowledge needed to be improved. The questionnaire was content validated by a group of nephrology nurses and a patient group. It consisted of 15 questions, response options of 1-5 in a Likert scale format. The higher the score, the more important the area of knowledge is graded.

Results

Visits and Preparations for Further Treatment of Uremia

The numbers of visits per participant varied between 1 to 8 during the study period (mean = 2,8). Fifty-six patients (80%) had two or more visits. The interval between visits varied from 1 week to 7 months.

More than half of the participants (59%) who had chosen a mode of treatment chose self-care dialysis (see Table 2). In our comparison group, 40% chose self-care dialysis (see Table 3).

Questionnaires on Self-Care Ability and Disease-Related Knowledge Needs

At the first visit, the participants were asked to answer the ASA Questionnaire, with a response rate of 74% of participants. At the second visit, the participants were asked to

Table 4
Disease-Related Knowledge and Educational/Informational Needs
(KEQ) Questionnaire

Disease-related areas of knowledge rated as most important	Disease-related areas of knowledge rated as most important to learn more about
“What happens if I refrain?”	“The effects of the disease on relatives”
“How can I continue my normal social and physical activities?”	“Self-care”
“What treatment suits me best medically?”	“What treatment suits me best medically?”
“How should I take my medication?”	“How can I continue my normal social and physical activities?”

answer the KEQ Questionnaire, with a response rate of 73%.

The perceived level of self-care ability, according to the ASA, was between 61-120 points, out of a maximum score of 120. Those who had chosen HHD estimated their self-care ability to be higher (mean ASA score = 98), compared with the whole nurse-led clinic population (mean ASA score = 90). The group that chose HHD was also younger; their mean age was 54 years compared with the whole nurse-led clinic population, whose mean age was 67. Results from the KEQ Questionnaire showed that self-care and effects of treatment options on family and everyday life were rated as the most important disease-related areas of knowledge (see Table 4).

Initiation of Dialysis

When dialysis was initiated, eleven (52%) of the participants started self-care dialysis. Four of started on HHD and seven on PD. As shown in Table 2, of those who started dialysis (n=21), 19 had a permanent and functioning dialysis access (AVF [n=11], graft [n=1], or PD catheter [n=7]). Ten percent of the participants started dialysis with an emergency dialysis access. In our comparison group, 39% of the patients who were previously known in the unit started with an emergency dialysis access (see Table 3).

The CKD diary proved to be a very useful and appreciated tool for

promoting self-care, disease-related knowledge, behavioral change and information, and in contact with relatives. The visits provided a good basis for health discussions about perceived quality of life, everyday situations, and health-promoting factors.

In summary, positive effects of the nurse-led clinic were evident, such as a greater proportion of participants choosing the self-care dialysis option, an increased proportion of functioning accesses at the initiation of dialysis, behavioral change (e.g., in the form of increased physical activity), as well as increased control and prevention.

Discussion

The major results of this study were that the participants in the nurse-led clinic both chose and started treatment in self-care alternatives to a greater extent than the patients in our historical comparison group (see Table 3). In the participant group, 52% of incident dialysis patients started with self-care dialysis compared to 33% in the comparison group. Nationally in Sweden 72% of patients start dialysis with conventional HD and 28% with PD. Of the prevalent HD patients, 3% have HHD (SRAU, 2006).

The fact that more patients chose self-care treatment can be seen as a result of improved disease-related knowledge and self-care ability, in combination with offers of and resources for PD and HHD. The

result can be partly explained by the fact that the nurse and the patient often met during repeated visits, which made it possible to gradually build on the patient’s disease-related knowledge and self-care ability. It is our impression that a well-informed patient, who feels involved and receives the support and encouragement that he/she needs before initiation of RRT, tends to choose self-care treatment to a greater extent. In our unit we also encourage Self-HD (SHD) to a varying degree, depending on individual ability. As the level of SHD has usually not been formed to the individual at the initiation of dialysis, it has not been used as an effect measure in this study. That means that the proportions of patients who, to some degree, carry out self-care dialysis at the initiation of the treatment at the clinic are not visible in our results. Also, the present results do not show what mode of treatment was considered by those participants who, at the end of the study, had not yet started dialysis. This will be very interesting to follow up.

The nurse holds a unique position in terms of providing education and support for the chronically ill (ICN 2000, 2006), in the complex care system. Providing patient education and supportive counseling places high demands on the nurse, especially if the aim is to achieve a permanent change in behavior (Rankin, Stallings, & London, 2005; Redman, 2004, 2007). Optimal patient education is focused not only on disease and disease management, but takes into account the overall view, quality of life and everyday lifestyle (Rankin et al., 2005; Redman, 2004, 2007). This is highlighted by the results of the KEQ Questionnaire.

The nurse-led clinic offered the participants increased access to the care system, increased opportunities for information and follow-up, and increased opportunities for asking questions and discussions. It also provided a better basis for individualized learning than in our earlier organization. The topics and issues that the patient wishes to discuss with the

nurse during the visit, often change in character as the patient approaches initiation of RRT. Then it is important that discussions and information about these topics are well timed. Attitude and communication technique are of great importance. We strived to encourage the patient's reflection about his/her disease, life situation, and role as a responsible cooperating partner. This can help the patient to make informed treatment decisions (ICN, 2003; UK Department of Health, 2002).

Another finding was that the visits provided a good basis for health discussions about perceived quality of life, everyday situations, and health-promoting factors.

The CKD Diary as well as the ASA questionnaire might constitute an interesting practical tool when discussing perceived self-care ability and which mode of dialysis treatment would suit the individual. This needs to be further investigated.

The period preceding initiation of dialysis is often a stressful one (Harwood, Locking-Cusolito, & Spittal, 2005). It can be seen as a time before entering the unknown, which is how the individual would view dialysis treatment. Watnick, Kirvin, Mahnensmith, and Concato (2003) report that depressive symptoms are very common at initiation of dialysis. A study by Klang, Bjorvell, and Clyne (1996) revealed that patients about to initiate RRT experienced a high level of anxiety. In order to make the transition as smooth as possible, it is important to prepare the patient both mentally and physically, that is, with a functioning dialysis access.

One result worth emphasizing is that nearly all the participants (90%) who started dialysis had a functioning, permanent dialysis access (AVF, graft or PD catheter). This is better than our comparison group as well as earlier national statistics. In our comparison group, 61% of the patients started HD with a permanent access (see Table 3). This can be compared to 75% in Europe and 54% in the USA, respectively (Pisoni et al.,

2002). In the nurse-led clinic, the patient's dialysis access was checked and the self-care involved was discussed. On several occasions, problems concerning the dialysis accesses were noticed in the nurse-led clinic and could be dealt with in time before initiation of dialysis.

Medical events, such as aggravation of infection, initiation of dialysis using an emergency dialysis access due to a deficient fistula/graft, exacerbation of fluid overload and hypertension, incorrect use of drugs, and admissions to hospital, were prevented during the study period.

Case Study

The preventive efforts could be exemplified by following case presentation. A 67-year old man, who had undergone vascular access surgery in preparation for HD 1.5 years prior to the first visit to the nurse-led clinic where physical examination revealed that the access had not developed correctly. This had not been noticed before either by the physician or the patient. Re-operation was carried out and the access was checked at several follow-up visits in the nurse-led clinic. Five months after re-operation, HD was initiated with adequate access function.

Increased contact frequency and behavioral changes outcomes could be exemplified by the following case presentation: A 64-year old woman with long-standing diabetes (adult) had gained 15 kg (33 pounds) in weight in 9 months, due to inactivity and improper diet. Her body mass index (BMI) was 33. Despite medication, a raised blood pressure (BP) was also noted. The patient made five visits to the nurse-led clinic and was followed up by telephone. Using motivational interviewing that was focused on behavioral changes, a care plan was formulated with clear, achievable goals. The care plan described how the behavioral change would be achieved in practice. The CKD diary was used for support during this process. The behavioral changes included increased physical activity, 10-15 minutes walking with

rest, which was increased to daily walks for 2 km (1.24 miles) without rest. The changes also involved a transition from irregular snacking to regular meals. After 6 months, the weight was stabilized, the BP had decreased from 160/95 to 130/80, and the patient experienced a subjective improvement of her breathing while walking. At the follow-up another 15 months later, the blood pressure was still at the lower level and the patient had lost 8 kg (17.64 pounds) and reached a BMI of 30.

By using motivational interviewing as a communication technique, the nurse-led clinic is of importance in terms of changing behavior towards improved health. The nurse-led clinic has resulted in more frequent contact with the renal unit, which ensures increased medical control and increased opportunities for prevention. However, one has to take into account the inconvenience for the patients of too many frequent visits to the hospital, so it is important to coordinate these as much as possible. Telephone follow-up may be a complementing alternative.

Guiding and preparing – physically as well as mentally – patients with renal failure who are approaching initiation of RRT is a demanding task for the renal care team. With diminishing financial resources, we have to optimize various health care efforts for this category of patients. Combining the medical treatment with nurse-led clinics increases the prospect of a well-prepared patient at the initiation of RRT. Cooperation with the physician responsible for the patient is vital. For this type of service, it is important to clarify areas concerning liability and safety. In addition to adequate training and knowledge on the part of the nurse responsible for the patient, a clearly-defined medical responsibility, defined goals and tasks, and good follow-up of the service are important safety factors.

One shortcoming of this study was that the comparison group was historical with retrospective data. Another shortcoming was the relatively small number of participants, which makes

it more difficult to generalize and draw reliable conclusions. However, our conclusions are in line with other controlled, randomized studies, in which the effects of nurse-led clinics on chronic disease have been evaluated (Denver et al., 2003; Griffiths et al., 2004; McHugh et al., 2001). Based on the results of this study, our unit made the organization with a nurse-led clinic permanent.

Conclusions and Recommendations

Although caution should be taken drawing conclusions, we could see that for the participants, the nurse-led clinic led to improved opportunities for learning, self-care, discussions and reflections on their health situation, and the influence of the disease on everyday life. The nurse-led clinic has also provided an opportunity for increased medical control and prevention. A nurse-led clinic increased the opportunity to prepare the patients, both physically and mentally, for the initiation of dialysis.

Implications

For the nephrology nurse involved in predialysis care, the nurse-led clinic may provide a challenge and an opportunity for professional development, and an opportunity to work more independently with education, structured communication, patient empowerment, behavioral change and prevention. For the patient, the nurse-led clinic can result in improved outcomes.

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Renal Clinical Nurse Specialist, rural area. Home first dialysis model of care. Page 6 of 39. The innovation: home first dialysis model. Case for change. Chronic conditions in Australia are on the rise, associated with an ageing population, and an increase in lifestyle factors impacting negatively on health. Outcomes of the SWSLHD Renal Care Pathway include introduction and use of a structured multidisciplinary predialysis pathway, introduction of a valid psychological assessment tool to support timely and appropriate referrals to a renal psychologist, and increased rates of home dialysis. Patients have also reported greater satisfaction with care, care coordination and preparation for dialysis.