

The role of the pre-dialysis nurse in New Zealand

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Abstract

Background: International evidence suggests that pre-dialysis care is crucial for patients with chronic kidney disease (CKD). Pre-dialysis nurses play an important role in this care.

Aim: This article describes and discusses the role of the pre-dialysis nurse in New Zealand (NZ). It presents findings from a larger qualitative study that explored what pre-dialysis nurses perceived to be effective care. Understanding their role was central to understanding effective practice.

Methods: Semi-structured interviews were used to gain in depth data from eleven pre-dialysis nurse key informants from throughout NZ about their role. Confirmability of findings was strengthened by an additional group discussion with all participants. Thematic analysis guided by a general inductive approach was used to analyse data.

Results: Five key themes emerged relating to the pre-dialysis nurse role: patient engagement and a holistic nursing assessment; the nurse as educator and support person; preventing complications; professional relationships and developing the role. The study illustrated the complexity and challenges that pre-dialysis nurse's encounter. There was some variation in roles and participants reported a lack of clear role definition.

Conclusion: The findings highlighted a need for more standardised pre-dialysis nursing care in NZ, such as the implementation of guidelines for nurse patient ratios and the components of patient education. Although various guidelines exist, none of these are specific to the nurse's role and the implementation of nursing care. Implementation of NZ guidelines would not only provide clarity to pre-dialysis nurses but also ensure more equitable care of patients throughout NZ.

Introduction

International literature clearly demonstrates that multi-disciplinary pre-dialysis care is effective in extending time to dialysis and improves quality of life, patient acceptance and treatment choice (Devins, et al, 2003; Devins, et al, 2005; Goovaerts, et al, 2005; Klang, et al, 1998; White, et al, 2002). The literature

also shows that pre-dialysis education is effective in reducing the requirement to start dialysis urgently, and for improving patient and clinical outcomes (Curtis, et al, 2005; Devins, et al, 2003; Devins, et al, 2005; Goovaerts, et al, 2005; White, et al, 2002). Despite this overwhelming international evidence of the effectiveness of pre-dialysis care, an "unacceptably

Key Words

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high level of patients [are] inadequately prepared to commence dialysis" (Owen, et al, 2006, p 145).

Pre-dialysis nurses play a central role in the provision of pre-dialysis care. This paper presents results from a larger study which sought to describe the role of pre-dialysis nurses in New Zealand (NZ) and identify what effective pre-dialysis nursing care encompasses, in order to improve care and patient outcomes (Walker, 2009). The paper specifically reports the research findings describing the role of the pre-dialysis nurse.

Method

The research study design was qualitative and a descriptive exploratory methodology was used (Schneider et al., 2007). The phenomenon of interest was defined as "any nurse providing pre-dialysis education and care in New Zealand". Fourteen nurses fitted that definition and thirteen of these received an invitation by email to participate in the research. The other member of the sample was the interviewer, whose insider status as a pre-dialysis nurse was acknowledged. Eleven pre-dialysis nurses consented to participate and all were classified as key informants, being experts in the field of pre-dialysis nursing. Ethical

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The role of the pre-dialysis nurse in New Zealand

approval was obtained through the New Zealand Multi-region Ethics Committee in June 2008.

Semi-structured audio-taped interviews lasting approximately one hour were used to gain in depth description and discussion from the participants about their roles and perceptions of effective pre-dialysis care. One open ended question at the beginning of the interview invited participants to describe their role as pre-dialysis nurses. This was, "Can you briefly describe what you do in your role?" In addition demographic data was collected during the interview.

All interviews were undertaken by one researcher (to ensure consistency) and in the interest of saving time and cost, all were undertaken by phone. The taped interviews were transcribed and the data was analysed using thematic analysis, guided by a general inductive approach (Thomas, 2006). This involved thorough reading and re-reading of transcripts to identify key themes in the data. Initial analysis was undertaken by the first author (the interviewer) and was reviewed by the other two authors. Preliminary findings were then fed back to and discussed with the participant group at an annual pre-dialysis nurses meeting, providing a member check (Schneider et al., 2007), and further refinement of themes and analysis was carried out.

Results

The demographic interview questions yielded a general picture of the participant group and the patients. In NZ all pre-dialysis nurses work in the public health system and are based in secondary and tertiary health care facilities. Participants worked throughout these settings holding a variety of titles which included Clinical Nurses Specialist (CNS), Co-ordinator, Specialty Nurse and Nurse Educator. Table 1 provides an overview of participants' length of time in their current position, post graduate qualifications and nurse/patient ratios. Of particular note was

Table 1: Background information about participants

	Time in Position	Post Grad Qualifications	Nurse Patient Ratio
1.	9 years	Renal Certificate	0.7 : 70
2.	7 years	Post Grad Cert	1.0 : 100
3.	7 years	Nil	1.0 : 155
4.	6 years	Nil	1.0 : 95
5.	4 years	Post Grad Cert	1.0 : 101
6.	3 years	Post Grad Cert	1.0 : 100
7.	3 years	Nil	1.0 : 70
8.	2.5 years	Masters	0.7 : 70
9.	2 years	Nil	1.0 : 180
10.	2 years	Undertaking Post grad Cert	0.6 : 61
11.	1 month	Nil	0.3 : 37

that there was some variation in nurse/patient ratios and that this was not related to the level of qualifications or length of experience in the role. Participants also reported that their case loads were increasing as the burden of CKD was increasing in the population.

A number of key themes were induced from participants' broad discussion of their pre-dialysis nursing role. These included a picture of the process of engagement with their patients which included a holistic nursing assessment, the provision of education and support to patients, nursing interventions to prevent complications and liaison with other professions. In addition participants talked about issues to do with defining their role.

Patient engagement and holistic nursing assessment

Participants began discussing their role by describing the process of their engagement with newly diagnosed patients. Effective engagement was considered a key feature of their role and involved responding to referrals, setting in place initial and ongoing visits and, importantly, undertaking a thorough holistic nursing assessment.

Engagement commenced with a referral, predominantly from the Nephrologist, to themselves, the pre-dialysis nurse. A few

participants also received referrals from renal registrars and renal clinical nurse specialists. The criterion used to refer patients to the nurse was an estimated Glomerular Filtration Rate (eGFR) that ranged anywhere from 15 to 30ml/minute, with no standard practice across the country. Participants reported some inconsistency of referral times; meaning patients were referred to them at different stages of kidney disease. Those referred in the late stages had more pressing needs and participants felt that late referrals had consequences for the kind of care they could provide.

A few participants identified a detailed clinical pathway for pre-dialysis patients, while in other cases the pathway or model of care was stated to be poorly defined. For the majority, the initial visit was predominantly to meet the patient, complete the initial assessment, provide the majority of education and assess the patient's ability to self care. Most initial visits were home visits where the nurse, sometimes accompanied by the social worker, visited the patient and their family or support people in their own environment. This initial appointment usually ranged from one hour to two and a half hours in duration.

Every patient gets a home visit, so that usually takes about one and a half hours and that just involves physical assessment as well as education. So we do, minimal

The role of the pre-dialysis nurse in New Zealand

social assessment, a bit of medical assessment. At the same time we try and do those with the whanau, at the times that are flexible.

Participants considered a thorough holistic assessment as crucial for planning the patient's care as well as helping them make appropriate and correct choices for their future treatment. The importance of being familiar with the patient, their lifestyles and their whanau (family) was also discussed. The majority of nurses completed the holistic assessment at the initial meeting with the patient and ongoing assessments at any future meetings.

We try and be quite holistic in our assessments, so we've sort of crossed everything off and made sure that it is going to be an appropriate treatment for them.

There was some variation in the reported length of time before follow up after the initial visit. Some participants had a defined follow up time period for each patient. For example, one rang each patient two weeks after the initial home visit, whereas two others had an alert system in place, whereby if they had not been in contact with a patient in a six month period they would be alerted. Most of the follow up, however, was planned on an individual basis, as and when required. In all cases the patients were given the nurse's contact details and encouraged to make contact with them as required.

The number of contacts each participant had with a patient varied. Most stated that the number of contacts was individualised and depended on the specific needs of the patient. A few discussed their inability to meet with the patient frequently due to time or geographical constraints. In fact, some commented on what they saw as disparities in services for patients living in remote or hard to reach areas.

The nurse as educator and support person

A strong theme in the data was the pre-dialysis nurse as educator and support person. This aspect of the role was

seen as crucial to ensuring patients were empowered and informed as they entered a new phase in their lives. Participants reported that a large component of their role and an important indicator of effective care was ensuring patients received timely and appropriate education. This involved ensuring they and their family were aware of the disease process and the way their body, lives and future might be affected. Also important was the adaptation of information or the nurse's ability to ensure that the information they delivered was appropriate to the patient's level of understanding and need.

Education, it's a priority, making sure they actually understand the situation. And it varies, I mean, some people you can give loads of information, other people want more direction. So we have to alter what they need to know.

There was, however, some variation in the amount of education patients received and some participants found condensing such important and extensive information very difficult if they only had one education session. They reported the lack of time to spend with patients to educate appropriately and to deal with the wide number of health, social and other issues patients needed assistance with, as very frustrating.

A number of participants facilitated group sessions for the pre-dialysis patients and their families, covering a wide range of topics. These commonly involved an informal session with a small amount of formal education and an opportunity for pre-dialysis patients to meet and talk to other patients who had already undergone dialysis or transplantation. Those participants who did not run group sessions still provided this support service by facilitating meetings with other pre-dialysis patients. Different group approaches were being trialled to assist accessibility for the patient, from culturally specific groups, for example, targeted to Samoan patients, to geographically defined groups.

A number of participants had initiated and run nurse-led clinics for the pre-

dialysis patients while others attended the physician-led clinic appointments with them. Some raised concerns, however, about the lack of support to implement nurse-led clinics or group education sessions.

Part of the pre-dialysis nurse's role also included promoting living-donor transplants and ensuring people were listed on the national transplant list. This, along with ensuring patients and their families were well educated on the benefits of transplantation, was described as a very important part of the pre-dialysis nurse's role.

We really try and promote live transplantation, and talk to people about how the process works, because I think that's a really important thing and it's certainly somewhere where we really try and be proactive.

Another large component of the nurse's role was talking about conservative or palliative management. Discussing death and conservative treatment was often talked about as one of the most challenging parts of the role.

We're doing a lot more counselling around not having dialysis. I think we are effective in perhaps providing people [with] the option of non-dialysis. I think that's been positive because they have been directed to palliative care services more appropriately and in the past some of those people have been put onto dialysis which would have been a very bad experience for them.

Preventing complications

Preventing complications meant using nursing skills in the broadest possible sense to ensure a patient's pre-dialysis condition did not deteriorate more rapidly than it otherwise might, and to mitigate complications. While some participants discussed this as an integral part of their role others did not. For some this was due purely to restrictions on time with the patient or being limited to one patient visit. The comment made by one participant, that spending twenty minutes discussing

The role of the pre-dialysis nurse in New Zealand

patient medications or good diabetic or blood pressure control was not good use of their time, was reasonable given the need to explain to patients in a short period about kidney failure and treatment options. Some participants, however, believed preventative care to be a key component of their role.

Preventing complications included monitoring patients' blood results. This was another area in which practice varied widely amongst participants. For example, one said that a lot of her role was "monitoring, transcribing and discussing blood results", and another stated "I know it's not my job but I track the monthly blood results so I know what's going on with all my patients", whereas other participants only viewed blood results when the patient was seeing the physician in clinic.

One participant stated, "we do a lot of junior doctor work". This included organising hepatitis vaccinations, 24 hour blood pressure monitoring and management and planning iron infusions. A few had a role in prioritising patients for vascular surgery and anaemia management, working with the physician to plan the initiation of treatment and modifying the patient's medications as required. Others discussed following up patients who did not attend (DNA) clinic as an important component of their role. As part of their preventive role some had a wider educational component, educating not only patients but also primary health care workers, including GPs and practice nurses; Maori health providers; other nurses; and student nurses.

Professional Relationships

Ensuring effective relationships with other professionals and services for the benefit of their patients was another theme arising from participants' discussions. Liaising with and referring to other members of the multi-disciplinary team and other services were considered imperative components of the pre-dialysis nurse's role. This meant they were both an integral member of the

multi-disciplinary team and an advocate for the patient. Most participants led a multi-disciplinary meeting to discuss patients. Meetings ranged from meeting with the doctor only, to meeting with the entire multi-disciplinary team, including palliative care social workers, dieticians, home training staff and diabetes nurses. In addition, some participants had set standards for cognitive assessments, using recognised tools such as the Mini Mental State Examination (MMSE) and referred to the occupational therapists if required.

The majority of participants referred all patients to the renal social worker and dietician. Referrals were also made to dialysis access, anaemia and transplant co-ordinators/nurses as well as physiotherapists, occupational therapists, diabetes specialists and psychologists, when appropriate and where they were available. The palliative care team also played a key role both as a liaison/support service and in receiving referrals for help with patients who had chosen conservative management. The majority of participants also referred patients to the home training units if the patient had opted for a home based treatment. Varying degrees of input were instigated by the home training team with the pre-dialysis nurse prior to the patient commencing home training.

Developing the role

In describing their role participants also tended to reflect on their experiences of developing it. A large majority of the participants were the first and only pre-dialysis nurse in their region and had therefore developed the role themselves. They reported no specific pre-dialysis guidelines or educational components to work from in developing their role, an experience mirrored by that of the interviewer and becoming a key motivator for the research. One participant stated

you get this job, I mean there's no educational material, there's nothing. You had a blank canvas and you start.

The majority of participants, therefore, shaped the way in which they delivered care and this was largely influenced by the support they received and the environment they worked in. Due to these factors the role of the pre-dialysis nurse in New Zealand encompasses a wide spectrum.

Discussion

This research yielded information from nearly all of the pre-dialysis nurses working in NZ and it enabled a comprehensive picture of the role of this specialist group. A particular feature of the research was the insider status of the interviewer (first author), a pre-dialysis nurse with a particular interest in and passion for the work of this group. The concept of insider research is not uncommon in qualitative research (Hewitt-Taylor, 2002; Bonner & Tolhurst, 2002) however, being an insider does pose a number of issues because of relationships with participants in regard to ensuring confidentiality and objectivity. These risks can and were minimised. Raw data and themes were cross checked independently by the other authors to ensure credibility (Schneider et al., 2007). There are, nevertheless, benefits of insider research in providing rich and depth of information (Hewitt-Taylor, 2002; Bonner & Tolhurst, 2002).

A possible limitation of the study was that almost all pre-dialysis nurses work in the North Island of NZ where the majority of the population reside and this is reflected in the participant group. It is therefore important that the findings are acknowledged as more indicative of the North Island. However, it might be useful for other centres where pre-dialysis services are not yet in place to use the research findings to help them plan and implement services.

In response to a broad invitation to describe their role, participants discussed their experiences and practices thus enabling an analysis of key components of the pre-dialysis nurse role. Participants

The role of the pre-dialysis nurse in New Zealand

described the pathway of care which they engaged in with patients as beginning with a home visit with a holistic nursing assessment. Patient education and support, the prevention of complications and ensuring effective inter professional relationships for the benefit of patients were other key components of their role. In addition, the nurses discussed that they had largely had to define their own roles as there was little in the way of role definitions or guidelines.

The majority of role components described here are consistent with those reported by Anand and Nissenon (2002) who saw the specialist nurse's role as the key success factor in disease management programs. They discussed in detail the role of the experienced renal nurse, who co-ordinated the care of 80–100 patients in close collaboration with a nephrologist and the multi-disciplinary renal care team. The nurse ensured that the prescribed care was delivered; kept in close contact with the patient with telephone calls, home and clinic visits; and encouraged compliance by educating patients about medications, side effects, harmful co morbidities and consequences of non-compliance. In addition, another primary goal of the nurse was to be the key facilitator of other referrals ensuring the system was not fragmented.

While a number of studies indicate that patient education is effective in improving outcomes for the patient and the service (Devins et al., 2003; Devins et al., 2005; White, et al., 2002), there is limited literature about what the education should involve and the best way to deliver it. The lack of guidelines regarding education was reflected in comments made by participants in this research and consequently the amount and content of education patients received appeared to vary according to each participant.

Variations amongst participants were evident in other areas as well. These included the number of patients which constituted a case load, the number of

visits/contacts each patient received, the length of follow-up times and whether patients were in fact followed up or just received one education session with the nurse. In the latter situation participants discussed their frustration and concerns about having to condense such important and vast information into one session.

The place and importance of preventative care in the role of pre-dialysis nurses requires ongoing discussion. With the increasing burden of CKD it is more than timely to effect change in this trend through wise use of preventative strategies. Participants considered this important but many expressed their frustration with issues such as lack of time, support or autonomy, which inhibited their ability to focus on this area (Walker 2009). After reviewing studies to identify the nurses' role in improved care for patients with CKD, Compton, *et al* (2002) suggested that the role should consist of not only educating patients and their families about kidney disease, symptoms and treatment but also monitoring laboratory results and medications to ensure the timely treatment of complications such as anaemia, hypertension, glycaemic control, renal bone disease, acidosis and deteriorating kidney function. Levin and Stevens (2005) also suggested that business cases had clearly identified that it was cost effective to slow the progression of CKD by using preventative strategies. Preserving renal function and prevention of progression Stage 5 CKD has also been identified as one of the essential goals of nephrology care (International Society of Nephrology, 2006; National Kidney Foundation, 2002).

The role of the pre-dialysis nurse is influenced by and in turn influences all aspects of the care the nurse delivers. This research identified that there is variation in the NZ pre-dialysis nurse role and a lack of clear definition of what the role should include. Benner (as cited in Bonner, 2003) recognised that in a

practice-oriented specialty it is imperative to understand the way the nurse practices and how expertise is acquired, as experts achieve the best outcomes.

This highlights the need for guidelines for the delivery of pre-dialysis nursing care and education as well as for what this education should encompass. According to Uhlig *et al.* (2006), clinical practice guidelines are important tools in determining the care of people with CKD by informing patient care, debate, research areas and policies. Guidelines would also provide new nurses in the role with a plan to develop their pre-dialysis programs and a guided plan of care. The American Nephrology Nurses' Association (ANNA) in its *Standards and Guidelines of Clinical Practice for Nephrology Nursing* incorporated a section on disease management focusing on patient education prior to Stage 5 CKD specifically to provide a comprehensive definition to benefit new nurses entering this area (Compton, Provenzano & Johnson, 2002).

In 2000, Kidney Health Australia and the Australia and New Zealand Society of Nephrology developed the Caring for Australasians with Renal Impairment (CARI) Guidelines to guide and improve management of kidney disease. The CARI guidelines recommend that approximately one year is required to optimally prepare a patient and their family/carers for kidney replacement therapy. Although these guidelines are used widely throughout Australia and New Zealand, there remains no national, standardised program of pre-dialysis care and education available in New Zealand or Australia (KHA, 2004).

Implementation of NZ guidelines for pre-dialysis nurses would help provide clarity and direction around the concerns raised by the participants in this research. The guidelines would provide direction on appropriate and effective care, provide new nurses in the role with advice to develop and plan their pre-dialysis

The role of the pre-dialysis nurse in New Zealand

programs and ensure equity of services and education to patients nationwide. It is acknowledged that rigid guidelines and prescriptive programs would not be appropriate to all areas as local contextual are important to consider. However guidelines which provide minimum standards for patient contacts, educational components and follow up times would provide some consistency, equity and quality of care throughout NZ.

In the NZ the roles of Clinical Nurse Specialist and Nurse Practitioner are evolving and there is an important opportunity to develop CKD and pre-dialysis programs with maximum benefits for the advancement of nursing practice and patient benefits. Bonner's (2003) research acknowledged that expert nephrology nurses undertook extended tasks that were incorporated into their practice through their holistic assessment. She found that the more nurses became advanced in their role the more they started to expand their practice. Compton, et al. (2002) agree and stated that "recognising the global benefits of CKD programs, nephrology nurses have an opportunity to expand their scope of practice and to impact on the long-term outcomes of this patient population. Nurses are pivotal in the success of these programs" (p. 335).

In NZ there are currently no specific renal nursing competencies. Nurses working at the expert level are deemed expert through NZ Nursing Council Approved Professional Development Programs. By identifying the specific roles and abilities of renal nurses, they are able to be recognised for their roles and their level of expertise.

Conclusion

This research provided a description of the key components of the role of the pre dialysis nurse in New Zealand. The detailed descriptions provided by the participants illustrated the complexity and challenges that these specialised nurses

face. Also highlighted was the need for clarity and relative consistency in the role of the pre-dialysis nurse. Implementation of guidelines would ensure that nurses have a foundation on which to base their role and care. They would also ensure that patients received more equitable treatment and care. The research clearly articulated participants' passion to provide the best service possible to all of their patients. It is now time to ensure that they are given the tools to assist them.

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