

## WHAT IS IMPORTANT ABOUT DISTRICT NURSING FOR PEOPLE WITH CHRONIC ILLNESS

### INTRODUCTION

**This newsletter articulates the research process and shares the findings of a study which aimed to answer the question; What is important about District Nursing for people living in the community with chronic illness?**

The prevention and management of chronic illness or conditions is at the forefront of the government's health agenda in Australia and in countries across the world. Chronic illness accounts for 80% of the total incidence of disease, mental health and injury in Australia (Australian Institute of Health and Welfare 2006). Onset of chronic illness may be slow, even though it can also manifest with acute episodes. While not usually immediately life threatening, chronic conditions are the leading causes of premature mortality and often life changing for individuals, family and communities.

Seventy three percent (73%) of clients of the Royal District Nursing Service (RDNS) live with two or more chronic illnesses, and of those, 49% receive RDNS services for longer than six months. Chronic illness care can be complex because often, multiple chronic illnesses are present, and there may also be complex socio-economic situations. Working with people in the care of chronic conditions is a large part of what District Nurses do.

District Nurses often care for people who are learning to live with chronic illness; hence they wanted to inform their practice by understanding what aspects of their care people valued. By prioritising research such as this, District Nurses demonstrate a concern for evidence-based best practice and ongoing development of their knowledge, skills and expertise.

### BACKGROUND

District nursing is a synthesis of public health practice, health promotion, Primary Health Care principles and nursing science (Cooney, 1994; Blackie, 1998). District Nurses have a unique role in that they work with people in the environments where they live and work, seek to improve health at the individual, family and community levels and locate the person or people as the 'expert(s)' of their lives. This approach fits well with people who are learning to live with chronic illness. Chronic illness can have far reaching implications for the individual and family, because there can be permanent effects on the person's body, sense of

well being, relationships with others, development of physical and mental health co-morbidities and significant disruption to an individual's quality of life (Kralik et al 2002). The prevention, management and interventions for chronic illness are at the forefront of the Australian government's health agenda and many countries across the world. The number of people living with chronic illness is escalating, with claims that many do not receive appropriate care due to a mismatch between their needs and the capacity of an acute care orientated health system to meet their needs (Bodenheimer *et al.*, 2002a; Bodenheimer *et al.*, 2002b).

A Chronic Illness Framework is being progressed at the National and State level with implementation at regional health service level through the GP Plus Health Networks. RDNS is involved as partners in this network. The framework and related literature were examined as part of this research because understanding the framework provides RDNS with an opportunity to reconcile the role of the District Nurse with the developed strategies. The research reported in this newsletter has helped RDNS to identify how District Nurses add value to the lives of people living in the community with chronic illness.

### WHAT DID WE DO?

A comprehensive literature review, incorporating published literature and Commonwealth reports, was undertaken at the outset of the research project. This literature review informed the development of interview questions with people with chronic illness and the District Nurses who care for them. Twenty in-depth interviews were conducted with 20 adult clients of RDNS who had two or more chronic conditions and had been receiving RDNS services for longer than 6 months. Simultaneously, twenty in-depth interviews were conducted with District Nurses of diverse levels and specialities working in the Northern Division. All interviews were audio-taped and transcribed verbatim. The research team then analysed the interview data to determine themes and subsequent meanings. The outcome of combining the interview data with knowledge gained from the literature review informed the development of a District Nurse led model for person centred care (attached). The research was conducted between January and June 2006.

### Ethical Considerations

Ethics approval was obtained for the conduct of the study. Nurses and clients were invited to participate in the research through circulation of a flyer. The purpose of the research was explained to all participants prior to the interview taking place and they were given the opportunity to ask questions. All participants (nurses and clients) were

informed that they could refuse to answer any questions and withdraw from the research at any time. The full report can be accessed via the Research Publications pages on the RDNS Intranet.

### **Interviews**

Examples of questions asked of people with chronic illness were; What chronic illnesses do you have and how do these illnesses impact upon your life? How do you manage these illnesses? What do you need/want in order to manage the impact of these illnesses? How are you supported by health workers? What have been your experiences of community nursing? What do you consider is important about district nursing? What does receiving district nursing service mean for the way you experience illness?

Questions asked of District Nurses working at diverse levels and areas of clinical specialities; How does district nursing makes a difference to the lives of people who live with chronic illness? What are the differences between the way you provide care to people living with chronic illness and to other people who don't have a long-term condition? What do you think is important about district nursing for people with chronic illness? What does having more than one illness mean for the way district nursing care is provided? How do you work with other health care providers when providing care for people with chronic illness? What are the characteristics of the relationships you have with people who have chronic illness? What factors enable or support you to provide best care for people living with chronic illness? What hinders or constrains your practice when providing care for people living with chronic illness? Interviews were conducted in a private setting and lasted between 30 and 90 minutes. Thematic analysis of the interview transcripts was undertaken.

### **WHAT DID WE FIND?**

The findings of this research revealed that district nursing care makes a profound difference in the lives of people living in the community with complex chronic illness. District Nurses bring together a unique blend of interpersonal, technical and psychosocial care which promotes the person's self-esteem, confidence and independence, and in doing so often averts the need for involvement of other services and enables the person to stay in the home environment.

The vehicle through which all of this happens is the relationship that nurses strive to develop with people. The relationship is the aspect of care most noted and valued by clients. The nurse's clinical expertise when responding to the demands of chronic illness happens within the context of a healthful relationship. Effective district nursing care occurs when expert clinical skills and knowledge coincide with empathy, expressions of caring, and valuing of the person. The long-term nature of the relationship between District Nurses and the person provides the familiarity and continuity pivotal to effective chronic condition care.

### **Perspectives of District Nurses**

District Nurses draw on a vast range of resources and services to ensure the client's needs are met. They are navigators of a complex service environment, bringing a mix of multi-disciplinary service providers into the

person's life. District Nurses are prime movers in the client's life, getting things done and making things happen in a way that family members were unable to do. The aim of nursing care is to improve a person's quality of life, whether it be making a wound less painful by the type of dressing used or by sharing knowledge with people about how to manage illness. The desired quality of life is determined jointly by the client's priorities and the nurse's expertise. This was achieved by working with the person to recognise the choices available. A nurse said:

*I think the main thing is it keeps them home where they want to be – with their families, hopefully, or with the supports, whatever they are, that they have around them. And minimising those trips to hospital etc, if possible, and maintaining their independence... I think that's a really important part of what we do... that we try to keep people as independent as possible, and encouraging them to be involved in their own care. And by that you can improve their quality of life I believe.*

District Nurses perform a multitude of tasks and roles relating to advocacy, information and education, self-management, health promotion, community liaison, clinical tasks, navigating and linking with community resources, empowering people, placing the person at the centre of care, case management, and holistic ongoing assessment and monitoring. District Nurses act as a resource to other services in matters regarded as important to the person. This knowledge and skill is seen as pivotal to alleviating the client's suffering and improving quality of life.

*They [clients] have the confidence that the nurse has that knowledge of the disease and also the knowledge base of linking in with other services, the knowledge of that broad community, the sort of resources out there.*

The client and family have a perspective of the disease and illness that is different from that held by health workers. District Nurses, however, have the opportunity to develop mutual understanding over time and are informed by the client's home context. When asked what people with chronic illness need most, one nurse replied:

*Understanding about how that chronic illness affects their whole life – not just how it affects the nursing actions that we're going in there to do, but ... that greater understanding... the social, the emotional, the physical, the physiological, the psychosocial – all those different aspects. They need understanding.*

One important component of a person-centred approach is that the nurse seeks the person's involvement in decisions about their health and lives, in order to place control in the person's hands. This is repeatedly referred to by nurses as a key factor in the district nursing approach.

*I think it's also their need to feel in control as well, that empowerment and that they're the active participant in their decision. I think that's the most important thing... is that we're very mindful that it's their condition and that again we're looking at a realistic plan of care that they've been consulted and involved in and that they have set.*

District Nurses value people in the context of their everyday life and adapt care to meet the individual person's needs. Nurses observe, listen and talk to the

client through their experiences of illness. Shared meanings evolve about what the client's experience of life with chronic illness is. Person-centred care is central to district nursing because care is informed by the person's needs, wants, wishes and priorities.

### **Perspectives of people with chronic illness**

People with chronic illness had confidence in the nurse's knowledge and skill. They experienced the benefits of nurses having expertise in diverse areas of care.

*I don't know whether that's her experience or whether it's the training that she's had, or what, but it feels more comfortable... I mean, she's putting some kind of gel in there ... and that makes it very comfortable, anyway.*

Isolation is frequently experienced by people living with a chronic illness and is in itself a form of suffering (Kralik et al 2006). District Nurses prioritise the person's needs and wishes, acknowledges personhood and demonstrates respect. The valuing demonstrated by the nurse is experienced by the client as 'being important'.

*Seeing them ... they make you feel important. Yes, they make you feel important. They're lovely and gentle.*

*...the nurse's job really is to look after the patient, but they do more than that... not a little bit, a great deal more to the person....And they make me feel... they make me feel good.*

Clients rely on and trust the nurse as a source of information. They know they will get honest, straightforward answers.

*I don't know what they're qualified for, but they're very good, they're extremely good and if I ask them anything they give me the answers. If I say ... what do you think about this? I asked her yesterday and she said you've decided to go on Clexane so you're going to need another authorisation and she said 'okay here's the form, you've got to get that done, any questions'? I asked her a question and she gave me the answer. They don't beat around the bush and say 'oh we don't know'... they just advise you to the best of their knowledge, which I think is great.*

District Nurses filled the information gaps created by disjointed or fragmented care filtering through from other parts of the health system. Nurses spent time ensuring that the client has the information needed. This was important to people who were anxious about unanswered questions.

*I'd probably to this day be wondering whether I was going to lose my legs in the future or not, but now I've got a much clearer outlook on my legs you know. Because of [the District Nurses] I can thankfully say that I've got 86% blood flow in this one and 92% blood flow in that one and if I keep my nails trim and keep my feet clean, and stay on a moderate diet, that I probably won't lose my legs.*

Living at home is highly valued, particularly when there are health issues which may threaten this. Many clients stated that without the support of the District Nurse they would need to be hospitalised.

*My dressing needs attending and if there's no support like that out in the community, well you know, people would never get discharged from hospitals.*

The monitoring role of the nurse and as the primary

person for intervention reassured clients.

*With [RDNS Nurse] coming around... okay, he comes here to fill the dosette box, but he's sort of like my primary intervention. If something's going wrong, then he will encourage me to go and see a doctor, or sort something out. He's like the first line of defence. We've discussed it, and I'm happy to be frank with him, and he's happy to be frank back. Our relationship is based on trust, respect, and a certain degree of friendship... well it's not friendship, but it's just a good relationship.*

Chronic illness may bring changes in the person's abilities. Ongoing monitoring of the client's health is vital to inform an assessment of their needs. Advocating on behalf of the client to be provided with the service is then undertaken. This takes away the burden of having to negotiate with health care services when unwell or coping with the consequences of illness. There is a sense that clients are happy for the nurse to take this role.

*I mean ... most times I don't have to call my doctor out if I need him... they've already done it.*

Clients value the nurse as facilitator of communication between the client and other service providers.

*Sometimes, the girls would write... a letter for Outpatients... they will write down on the form what they've been doing and the hospital have got to answer to that...*

Accessibility is optimised when the nurse comes to the home. Clients recognise that the District Nurses are more accessible than the GP or the hospital staff. Clients perceive that District Nurses are able to spend time attending to the person's needs whereas they feel that GPs are unable to do that. District Nurses have a better knowledge of the health issue because they see and deal with the issue regularly.

*[I rely on]...the nurses, because they're here all the time...they see it all the time – the hospital doesn't.*

The client can rely upon the nurse to be there when they need it.

*As I say, if I really was sick, I know they'd be there to help me.*

*I can lie in bed and know that if I'm not feeling too good when they're coming here I knew that the nurse would come and fix me up you know.*

District Nurses assist people to feel safe; to know that there will be someone coming who will attend to their needs. For people who live with a great deal of uncertainty because of illness, the sense of security that visits from a District Nurse provide is highly valued.

### **DEVELOPMENT OF A MODEL OF DISTRICT NURSING CARE (attached)**

The District Nurse model for person-centred care specific to people with chronic illness was developed from the findings. The model articulates the values and role of the District Nurse and the valuing of the person with chronic illness. The knowledge and expertise that the District Nurse has is combined with the knowledge and expertise that the person with chronic illness has about their daily life. We now briefly describe the important elements of the model.

The relationship between the District Nurse and client is

primarily professional but includes familiarity with the person's life, the high level of trust and respect invested in it, and the continuity of the relationship. This creates an environment where the nurse makes a significant personal contribution through interaction that demonstrates valuing and respect for the person. The positive impact of this on the person's sense of self and experience of life is marked. People feel acknowledged, validated and valued for the person they are. Understanding of the person within their life context ensures that other components of the system are included in interventions. Regular visits to the person provide opportunities for monitoring of the person's health status and functioning. It also enables the nurse to identify when another service might assist the person to improve quality of life. The nurse acts as an advocate for the person negotiating for the engagement of workers who can provide support with care. They also interpret information provided by other health care services and convey it to the person in a language that is meaningful.

The District Nurse assists the person to problem-solve the challenges that arise when living with chronic illness by providing alternative choices and options. The person trusts the District Nurse and decisions are made in partnership about how to manage the challenges. District nursing is guided by principles of primary health care which emphasises the importance of understanding life context, working with people and the collaborative involvement of other services in meeting the person's needs. People and services work collaboratively to achieve optimal outcomes for the person, hence there is emphasis is on the knowledge of wider health resources and services.

RDNS Clinical leaders and specialist nurses supported the nurse to find options for the person. The District Nurse draws on knowledge, skill and evidence-based practice in navigating the service network, making referrals and linking the person with the most appropriate service providers. The mix of service providers will change as the person's health and abilities change. The smooth functioning of the health care network for the person is facilitated by the role that the nurse takes in liaising and communicating with the various services. The District Nurse has a high level of credibility in the health care network and acts as a key reference point for the client, providing information as appropriate to services involved in their care. At all times the nurse ensures that the person has information and understands about each aspect of care.

### Limitations

This piece of qualitative research has high value as an investigative tool that will allow RDNS to understand the perspectives of both nurses and clients. Many aspects of the district nursing role are intangible and unquantifiable, making the measuring of effectiveness

difficult, yet there is a need to make quality explicit and demonstrate the impact that District Nursing makes in the community and the value it adds to lives of clients.

Whilst this is a rigorous, relatively large qualitative research inquiry in terms of the number of participants involved, we cannot be confident that the findings are representative of all RDNS nurses and clients.

### CONCLUSION

This research has highlighted the importance of the interpersonal relationship District Nurses have with clients as an element of care entwined with the technical aspects of care. At a time when chronic illness care is generally fragmented and sub-optimal, clearly the care provided by District Nurses to people in our community with chronic illness is highly valued but is also significant in order to maintain people in their home environment. One outcome of this research is the development of a model for person-centred care specific to the home care context. This care model clarifies the values and role of District Nurses and can assist nurses in the provision of effective care for people with chronic illness. In summary, important elements to this model are that:

- *The person is involved in decisions about their care*
- *The person is viewed as one part of a wider system*
- *All parts of the system are targeted for nursing intervention*
- *There is typically a close relationship between the nurse and person which is central to working together*
- *The nursing approach is humanistic and valuing of the person*
- *The nurse occupies a significant position in the person's life*
- *The nurse is pivotal in connecting services with the person*
- *The nurse works through relationships with the different people in the client's life*
- *Evidence-based practice and sound clinical knowledge and skills inform all that the District Nurse does*
- *Care is provided in the person's familiar environment*
- *Clinical knowledge and skill is the platform upon which all work takes place*

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