The Pursuit of Excellence

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Promoting Evidence-Based Nursing Practice:
What do people with chronic illness want from district nurses?

A chronic illness is one that persists over time without an easily definable beginning, middle and end. While the symptoms that accompany a chronic illness may be alleviated to some extent, the illness itself is not curable. More than 70% of RDNS clients live with a chronic illness. Given that working with people who have a long term condition constitutes much of the work that district nurses do, it seems important to ask:

What do people with chronic illness want from district nurses?

The information presented here has emerged from the findings of our chronic illness research program. For the last eight years we have been researching with people who are learning to incorporate illness into their lives (please refer to our many project reports & publications found on http://www.rdns.net.au/research_publications/).

We have come to understand that often the difference between controlled and uncontrolled chronic illness is the client's level of involvement. The old models of care, in which clients play passive roles, do not work for people who are learning to incorporate chronic illness into the rest of their lives. Effective chronic illness care requires a team of active participants, with the client being the most important member of that team. Most chronic illness care is not provided by nurses, doctors or other health care professionals but by the person who has the illness.

The district nurse may be the expert in clinical matters, but the client is the expert in his or her own life. The district nurse's key roles are to provide clinical expertise, to collaborate with the client to find solutions and to offer support:

- Clients are usually hungry for clinical information. It is important for people to understand that their daily decisions may have a major impact on their health and well being.
- Clients who are learning to live with a chronic illness need support to make significant and life long behavioural changes. One way this may be achieved is by working with people to set goals.
- The client's goal related to his or her condition or situation should be a driving force behind the district nurses' visit. Consider documenting the clients' goal in the care plan.
- To help clients set goals, work with them to explore the issues they're dealing with and to identify the real issues confronting them.
- Before offering what you think are the solutions to clients' problems, allow them to do some problem solving of their own.

Non-compliance has been documented as a significant challenge in chronic disease care. Labelling people as non-compliant is counter productive. Instead it is important to work with people in identifying what are the issues of importance from their perspective. Our research has demonstrated some key points:

- Models of care, where nurses and doctors tell people what to do and try to motivate them to change, are not effective.
- Because clients' day-to-day decisions have a tremendous impact on their health, they must be acknowledged as active, informed participants in the health care process.

What can district nurses do?

District nurses may help clients self care by working with clients to set self care goals. Consider the differences between two clients who have type-2 diabetes. One client's condition is well managed and the other's condition is not. Why is one more successful at controlling the symptoms than the other? Very often, the key difference may be the client's level of involvement in his or her own care.

Do as I say model

Our health care systems are not always designed with the client in mind. Unwittingly health care professionals do little to assist clients to self care. It may be that our health care is based on the acute-care model, where the client presents to his or her nurse and the nurse tells the client what to do to get better. It is a "do as I say" model of care. The client's role is often passive.

The 'do as I say model' may work fine in crisis medical events in acute care. The health care professional is the authority trying to get the client to do what they believe is needed; the client's job is simply to be obedient. Our research findings show, however, that you can't get clients to 'do' anything. The motivation to change one's behaviour -- even to take one's medication -- is a decision taken by the client. The client is responsible and often prefers to take an active role in his or her own care. The 'do as I say model' does not work well for people learning to live the rest of their lives with chronic illness.

The failure of 'do as I say models' of care for people with long term illness has led us to ask, what kind of approach can we use to work with people who have chronic illness? In other words, how can we change chronic illness care so that it better fits with the experience of living with a chronic illness?

The client is at the centre

We have learned over the many years that we have been researching with people who have chronic illness, that effective self care requires two things. First, it requires a team approach with the client at the centre. Second, it requires active, involved participants -- especially an active, involved client. This model of care can be described using various terms -- empowerment, informed choice, client centred -- but they all have the same underlying concept: The client is at the centre and is actively involved in his or her own health care.

Why does the client need to be involved?

We suggest there are several reasons. On a day-to-day basis the client is in charge of his or her own health. Of

course health care professionals are important but it' is estimated that between 95 and 99 percent of chronic illness care is given by the person who has the illness.

Each client is the expert in his or her own life. As a district nurse, you can suggest what is best for managing a wound, diabetes or asthma or congestive heart failure, but that does not mean you necessarily know how clients can best manage that illness in their day to day lives. You will not always know the details of a client's life: what's most important to them, what their other priorities are, what motivates them, what their financial situation is, and so on.

As a district nurse, you can think of your role as providing clinical expertise and information, collaborating with the client to solve his or her problems and supporting the client throughout the process. You could say: "Here's what I know about diabetes. How can I help you put this in context in your life so that you can make decisions that will help you?" This new mind-set requires that you give up any illusion you may have that you have control of and are responsible for your clients. Instead, consider yourself responsible to your clients -- to tell them, to advise them, to warn them. You cannot make their decisions for them and you cannot make them change their behaviour. Only they can do that.

Finally, our research suggests that when clients are encouraged to be more involved and when nurses are less prescriptive, clients perceive they have better outcomes. We also know that this approach does not take any more time but, in fact, can be more effective because the nurse is addressing the client's agenda first -- and the client's agenda is, after all, the reason for your visit.

When you create a partnership and opt out of the role of simply telling clients what to do, you pave the way for clients to make significant, lasting change in their lives.

Just as client-centred care can be more effective, client-centred education is more effective education. We suggest that you abandon education programs where people are lectured. This does not work any better than sitting them down and telling them to "lose 20 kilos" or "stop smoking". Instead, the client's needs should drive the education. For example, education can be based almost entirely on questions from the client. You may have a checklist of topics you want to cover, but those topics can be addressed in the context of client questions rather than through an impersonal lecture. Clients just are not as interested in their disease from a clinical perspective as we are. They want to know about themselves. What does this mean to me? How is this different for me? How is this going to affect my life?

What clients need to understand and what you can do

Four of the most important lessons clients with chronic diseases need to understand are the following:

1. They need to learn to live with the consequences of having a long term condition. Reiterate that they are involved in a learning process.
2. Their condition is essentially self-managed. Every decision clients make throughout the day, from what they eat to whether they walk or ride the bus, has an influence on their health. Communicate to clients that they are the most important individuals in managing their illnesses.
3. They have options. There is rarely one perfect way to treat a condition. In the case of diabetes, for example, clients can be treated through diet and exercise, oral medication, insulin and so on. You can help clients understand the different treatment options available and should be encouraged to look at the personal costs and benefits of each. Only the client can decide if the benefits are greater than the costs.
4. Rarely do clients leave the doctor's office and immediately enact whatever change was recommended. Life is full of changes and fluctuations. What works one day may not work the next. Talk with clients about significant behavioural changes that can be made by setting goals, taking that first step and figuring out what they may learn about themselves along the way. They can change their behaviour but it may take time to do so. Assure them that they will have your support.

Helping clients set self care goals

The driving force behind each client visit is the client's agenda or goals related to his or her condition. Ideally, the goal is clearly displayed in the client's care plan, and each person who handles the plan plays a part in supporting the client in that goal, asking, "How did it go? What have you done this week? How can we help you do better?" The process of setting "self care" goals with the client involves essentially three steps:

1. Look…Find the issue. Rather than beginning the client encounter focused on test results begin by saying, "Tell me what concerns you most. Tell me what is hardest for you. Tell me what you're most distressed about and what you'd most like to change." At the same time, help the client identify their strengths.
2. Think….When you begin to get a sense of the client's concerns, explore those issues together. Ask, "Is there an underlying problem? Do you really want this problem to be solved? What's the real issue?"
3. Act… Develop a collaborative goal. Once you have worked with the client to identify the issue, your instinct may be to try to solve it, but don't. Do not try to fix it. Instead, validate the client's feelings and his or her capacity to deal with the issue, and continue asking questions that will lead the client to his or her own solution. Ask, "What do you think would work? What have you tried in the past? What would you like to try?" You will find that you have helped build their capacity.

It is always more meaningful when clients find the "ah ha!" on their own, so give them that chance. Encourage them to come up with ideas first, then offer your own suggestions or additional information that they may need. You can say "this works for some people" or "have you tried this?" or "here's why I don't think that's a good idea." The important thing is to give the client the opportunity to say "no" and to make the final decision on what goal to try.

At the end of the conversation, the client will be able to tell you one step he or she is going to try. It should be very specific. If the client says, "I'm going to exercise more," ask what that means. Will they exercise four

times a week? What activity will they be doing? How far will they walk? Help them to come up with a specific plan that they have created for themselves. It may not be the ultimate goal you would have chosen for the client, but it's one they are more likely to accomplish. At later visits, you can build on that.

Who actually works with clients to set their goals, whether it is you or another nurse is less important than the fact that clients are encouraged to be the decision makers. The emphasis on self care goals suggests that the visit is for them. It is their agenda, and they are active participants in the outcome.

Sharing information

One way to help clients focus and begin thinking about health care goals is to talk with them about their individual health measures (such as blood results, blood pressure, HbA1c) and what those numbers mean. People who we have researched with have shared how important it has been to them when living with a long-term illness to have access to test results. One research participant said: "I find having the results and reports invaluable. I can compare my results with previous ones and know exactly whether or not I'm improving, I'm static or if my levels are dropping". Offering an explanation of what the numbers mean (ideal and actual) can lead to conversations about strategies for improvement. When faced with results from tests, clients may see for themselves where they may be struggling and what they can do to improve their results.

The 'real stuff' of nursing

The emphasis on facilitating clients towards finding their own solutions may go against years of training as a nurse. We often feel most helpful when we have given advice. But our research indicates that we don't really help people solve their problems or make lasting changes in their lives by telling them what they should do. Ultimately, clients need to find their own solutions.

District nurses are in an ideal position to facilitate people toward self care. This process is enhanced when the expertise a person brings to the management of their condition is given the respect it deserves. It is the 'real stuff' of nursing when we focus on practice that provides people with the means to grow and learn in a participative relationship.

The steps of goal setting

STEP 1: LOOK

1. Talk with the client to determine the issue.
2. Ask them why they think they are experiencing the issue.
3. Find out what is important for them.
4. Identify strengths.

STEP 2: THINK

1. Talk with the person so as to understand the possible reasons for the issue.
2. Assist by offering information or resources.
3. Work with the client to consider strategies that may address the issue.
4. Be creative and supportive so as to promote capacity.

STEP 3: ACT

1. Discuss the possible strategies with the individual. Does he/she think they are helpful?
2. Find out what strategies the individual would like to try.
3. Develop a plan of action and review it on your next visit with the client. Consider documenting it.
4. Provide positive reinforcement and feedback (promoting capacity).
5. Review the action plan and modify strategies or develop new strategies as needed.

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