



Promoting Evidence-Based Nursing Practice:

Putting the 'Self' into Asthma Self-Management: One Person's Story

The majority (75%) of clients receiving RDNS Services live with a chronic illness or condition. In response, the RDNS Research Unit has developed a chronic illness research program. To date we have completed 13 externally funded research projects, and we work closely with the participants of our research (over 200 community dwelling men and women) to build the findings collaboratively. Participatory Action Research (PAR) has been the methodology extensively utilised and we have expertise in its delivery. In this paper we report on a study completed in June 2003, where we explored self-management with older people who live with asthma. Key objectives were understanding from the perspective of older men and women living with asthma how the illness has impacted on their lives and to identify the contexts, barriers and issues that are significant for older people living with asthma.

Context

Over two million Australians have long term asthma. One in ten adults have the disease making incidence of asthma here one of the highest in the world. It has been clearly shown that asthma incidence is rising in the population with the greatest rises in children. However incidence over recent years in adults has reduced to one of a number of potential factors. Either a reduced incidence of asthma onsets in adults or perhaps that reported symptoms of asthma have been falling in later life as a result of better control measures (ABS 2002). Mortality from asthma is low but there is a marked difference in the rates between people under 35 years old (1 death per 100,000) and people over 65 years of age, particularly women (22 deaths per 100,000) are at greater risk (ABS 1999). Asthma is the fifth most common reason for people to consult general medical practitioners (AIHW 2002). All of these factors have led to asthma management in older Australians being placed as the sixth National Health Priority Area for the Commonwealth Department of Health and Ageing.

Asthma education and self-management are key areas of the guidelines in the National Asthma Council's Asthma Management Handbook (2002). Little is known of the issues that specifically impact on older people living in the community regarding strategies used to self manage their asthma. Little is known about the barriers encountered while attempting to self manage. This project moved one step closer to answering these questions.

The study

Twenty four older people participated in this study. We conducted one on one interviews exploring their experiences and the barriers encountered in successfully living with asthma. We then conducted two PAR group sessions allowing the participants to explore and learn together what it means to self manage their chronic condition. In the effort to answer the question: what is self-management, we explore the way in which one person was able to self manage and in this paper we present Jenny's story (note Jenny is a fictional name).

Findings

The epitome of management of asthma appeared to be taking medications. Closely tied to taking medications, was following orders from the medical officer. The most important point raised here was that the use of medication was something that was always done. Mostly people take responsibility for management of their medications. In addition to taking medications, prevention of asthma attacks was linked to identification and avoidance of triggers. Included in their

accounts were actions that could or have been taken. Preventive strategies were suggested such as sucking a lozenge when a cough or wheeze was first experienced. It was recognised that asthma fluctuates as life and the illness presented new challenges. In the section to follow we share Jenny's story of self-management.

Jenny's Story

In contrast to older participants with stable asthma, Jenny could not afford to ignore her asthma. She has had severe and brittle asthma since the age of seven:

I started off on adrenalin intravenously. He'd (the doctor) come 3 or 4 o'clock in the morning and give me it gram by gram. Once Ventolin came in it was like a wonder drug. The longest I've been in hospital with asthma is seven weeks. I was on oxygen for three weeks and prednisolone for a long time and gradually weaned of this. The longest I've been on prednisolone with asthma is nine months non stop. I blew up like a balloon. The last time I was in hospital was August of last year and I was in there then for two weeks with asthma. I'm called a chronic brittle asthmatic which means I can crash at any time.

At the moment her asthma management routine includes:

1000mg Flixotide daily, 1 puff twice daily of Foradile, a peak flow test before and after medications. I'm still on a 1000 Flixotide. I've been well since August. I am having a regular lung function test.

Despite diligent asthma management, a number of emergency admissions to hospital have left their mark on Jenny. Jenny talks about her fear:

It's really scary when you can't breathe. You feel you're going to die because you can't get your breath. Especially when you keep puffing Ventolin and using your nebuliser and you're not getting anywhere. Its very scary.

Jenny is vigilant about all aspects of her life with asthma and is particularly alert to triggers. She spoke about the impact of asthma on her every day life and her effort to reduce triggers:

It is usually a virus that does it. I am aware of things I am allergic to so I stay indoors if it's very dusty and the pollens and things are blowing around. We couldn't go out anyway because smoke's a very bad thing for me. The cold air - if I go from a very warm spot to cold air it affects me straight away. It just gets really bad.

Asthma is part of life. Jenny has incorporated this condition into her life and has been able to move on. She makes comparisons and prefers having asthma to diabetes. Her family's health history has provided her with a context to place her own illness experience:

My daughter got diabetes when she was ten and we thought that was the end of the world. My two sons - one was born with asthma but that was diagnosed with bronchiolitis until he was two. Usually with babies, they have a lot of respiratory problems. The other son now 33 didn't develop asthma until he was 9. He was a chronic bronchitis sufferer until then and had hay fever as well. The son with asthma from birth also had eczema as well.

Surrounded by people who live with a chronic illness has made Jenny resilient, but the pathway to self-management is not smooth. There were always other aspects of care that demand attention. These hurdles are part of self-management. Taking control involves exercising regularly and Jenny believes that it improves her lung function and general well-being. Jenny has other chronic conditions that vie for her attention, but she knows her limitations:

Arthritis doesn't get in the way? No, you push on. So what if you have a bit of pain. I think it's important to do gardening even if you are a bit breathless – you know your own limitations. I don't do nothing just because I'm an asthmatic.

Taking control meant taking some risks. Gardening was one activity where the boundaries are tested.

Jenny is able to incorporate breathing information into her everyday management. It was by chance that a physiotherapist consultation occurred after a referral from hospital.

A multidisciplinary team support Jenny's asthma management. Jenny has regular contact with her GP who runs an asthma clinic. She also visits a respiratory consultant at her local hospital every few months. These partnerships are vital for her but she doesn't see self-management of her asthma as just surrendering control to these health professionals. She works with them to prevent and sometimes treat exacerbations:

Yes I think it's important because I can crash so quickly. I feel more confident. I wouldn't have the confidence probably to go from day to day unless I had that backup from my doctor. Self-management is knowing when to increase your dosage and knowing when you need help. That's the way I'd interpret it. I do because I know when I'm in trouble, I know straight away. I do it (increase the dose) then go straight to the doctor, yes. Because he's often told me to increase it. I use the Ventolin and see the doctor straight away and he tells me what to do. I know to increase it anyway, but I like to have his supervision there as well. That's the biggest thing. Having someone you can rely on to help you straight away.

Having emergency contacts and resources on standby is vitally important for Jenny. Jenny made this her key suggestion for all people with asthma:

Find a doctor that runs an asthma clinic and has an educator.

It was by chance that Jenny knew of Asthma SA. Despite her significant history of asthma she had not heard that this organisation was a source of information and support. Jenny is not alone here. Her regular contact with a committed and informed GP as part of an asthma clinic provided her with support and education.

An asthma management plan is not in use but it is clear that Jenny monitors her asthma closely. Absence of a plan cannot be interpreted that the person with asthma is not managing, as Jenny observes:

I had one but as you get older your volume of air capacity changes so really the one I've got now is probably not valid. It (the plan) was useful to a certain extent but when I get a severe attack I can't breathe anyway so I know I have to go to the hospital, its not a matter of testing then because you couldn't test it.

Discussion

Stories from Jenny and others provide us with examples of a continuum of asthma management. At one extreme we find some older people whose asthma management can be seen as provided under a 'traditional' model of care, where health professionals are the experts and tell patients what to do. The continuum extends to the other level of self determining or self agency model of care where the person with the chronic illness is the expert. At this level it is the person with asthma who decides who and when to call for assistance. Jenny is located here, after considerable effort and self determination. Granted her asthma is brittle enough to need significant skills in self monitoring to ensure she stays out of hospital but she has also made choices to control asthma rather than letting it take control of her. Where many others situate themselves is at a level of collaborative care where expertise is shared between health professionals and the person with asthma. This may be a transition for those used to having their health managed by others. It can also be where someone who is self determining in terms of their asthma management moves in a time of crisis or exacerbation of their condition. Jenny situates herself in this collaborative care model when she is acutely ill but strives to return to managing herself when possible.

What becomes evident after reading these accounts of older people's lives with asthma is that there are diverse levels of personal ownership of their disease, varying levels of personal control taken over management of asthma and significantly a varying level of professional and structural support from the health system. This has significant implications on how District Nurses assist older clients with asthma in the care planning process. How we view responses to any chronic illness requires critical reflection and collaboration with clients.

In this study, the major constraint to self-management was its narrow conception as solely medical management. Much of the literature assumes that self-management means the same to all people, both professionals and those living with a chronic condition. Participants with asthma since childhood such as Jenny were experts in their own self-management although not always acknowledged as such. They were conversant with medical asthma management in the first instance and managed the 'self' in the context of their lives in the second. They were expert about their own lives. How can health care professionals provide support when people are learning to undertake self-management activities? Is this aspect of learning self-management not as important as medical education? It is our argument that both aspects, medical management and management of the self, are given scope and platform, and offered concurrently.

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The full report of this research project will be available on the RDNS website in August 2003. www.rdns.net.au (see *Research and Publications*).

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