

Improving Health Literacy in Seniors with Chronic Illness

April 2012

**Productive
Ageing Centre**

**National Seniors
Australia**

© National Seniors Productive Ageing Centre 2012

The National Seniors Productive Ageing Centre (NSPAC) owns copyright in this work. Apart from any use permitted under the Copyright Act 1968, the work may be reproduced in whole or in part for study or training purposes, subject to the inclusion of an acknowledgement of the source. Reproduction for commercial use or sale requires written permission from NSPAC. While all care has been taken in preparing this publication, the NSPAC expressly disclaims any liability for any damage from the use of the material contained in this publication and will not be responsible for any loss, howsoever arising, from use or reliance on this material.

Publisher NSPAC ABN 81 101 126 587 ISBN 978-0-9871249-8-2

The Australian Government accepts no responsibility for the accuracy or completeness of any material contained herein and recommends that users exercise their own skill and care with respect to its use.

The material in this Report may include views or recommendations of other parties, which do not necessarily reflect the views of the Australian Government or indicate its commitment to a particular course of action.

A reference to a particular person, organisation, product or service in any part of this Report in no way implies any form of endorsement by the Australian Government of that person, organisation, product or service.

The Australian Government disclaims to the extent permitted by law all liability for claims, losses, expenses, damages and costs the user may incur as a result of, or associated with, the use of the information contained herein for any reason whatever.



Australian Government

Department of Health and Ageing

Improving Health Literacy in Seniors with Chronic Illness

April 2012

Productive
Ageing Centre

National Seniors
Australia

FOREWORD

The rising burden of chronic disease in Australia has put the health system under great pressure. A system largely designed to cope with short bursts of acute illness via hospitals and general practitioners now has to deal with more chronic illnesses. The ageing population means there are more people faced with the slow decline of physical and mental function, and the distress and bewilderment that can bring. Consequently, the health system and the community generally need to focus on social support as well as medical problems.

One health policy response has been to call for stronger patient engagement. This means patients know more about their condition and have the confidence to manage their illness at home and make informed decisions. Patient engagement is recognised as a central point in most chronic care models, often described under self-care, self-management programs and self-management support. It makes sense for governments trying to keep health systems financially viable, and for patients and carers wanting more control over their lives and health.

Health literacy underpins patient and carer engagement and facilitates informed decision-making and self-management ability.

This report examines health literacy in detail. How do patients and carers learn about disease management? How do they develop their self-management abilities and learn to navigate complex health systems? What is the patient and carer experience of managing chronic disease?

Peter Matwijiw
General Manager Policy and Research
National Seniors Australia

April 2012

*The authors of the study on which this report is based are
James Gillespie and Justin McNab from the
Menzies Centre for Health Policy at the University of Sydney.*

ACKNOWLEDGEMENTS

The work – fieldwork, conducting interviews, analysing the transcripts – was carried out by the members of the Serious and Continuing Illness Policy and Practice Study. Particular contributions were made by Yun-Hee Jeon and Carmen Pearce Brown. The work at Mount DrUITT HealthOne was completed by Justin McNab.

Many thanks are due to the organisations and health care providers who helped the study from the start. The (then) Sydney West Area Health Service, WentWest and Blue Mountains Divisions of General Practice and HealthOne Mount DrUITT have all been generous with their time and access to staff and patients.

This has not been a study of the health care system itself, but of the experiences of those navigating their way through its labyrinthine services. We are grateful to the patients and their carers who agreed to be interviewed, and gave us an insight into the experience of living with serious and continuing illness, and often managing successfully against the odds.

This report and the associated research were funded by the National Seniors Productive Ageing Centre. National Seniors Australia and the National Seniors Productive Ageing Centre gratefully acknowledge the financial and other support provided by the Australian Government to the National Seniors Productive Ageing Centre project.

CONTENTS

Foreword	ii
Acknowledgements	iii
Introduction	1
The Policy Background To Stronger Patient Engagement	2
What Does Health Literacy Mean?.....	2
Different Definitions Lead To Different Approaches	3
Health Literacy At Low Levels In Australia.....	3
What This Report Does	4
Methods	4
The Study Population	4
The Serious And Continuing Illness Policy And Practice Study (Scipps)	4
HealthOne Mount Druitt	4
SCIPPS: Voices And Case Studies From Western Sydney And The Australian Capital Territory	5
Findings – The Scipps Study	5
Facing Uncertainty.....	5
Learning Through Formal Encounters	6
Learning Through Informal Encounters	7
Learning From Experience	8
Learning From Experience - Trial And Error.....	9
Learning From Experience - Observational And Reflective Learning	10
Findings - The HealthOne Mount Druitt Program	10
Health Literacy – Summary Of Patient Experience	10
The Hospital	10
General Practitioners (GPs).....	11
Community Health.....	12
Medication	13
Information/Mobile Technology	14
Community Approaches To Health Literacy	14
Conclusion	15
References	16



Improving Health Literacy in Seniors with Chronic Illness

INTRODUCTION

This report examines health literacy in detail. It describes some of the common learning processes used by patients with chronic illness and their carers to develop better self-management techniques. We draw on the experiences of people living with chronic illness in Western Sydney and the Australian Capital Territory. The report then looks more closely at how people with serious and continuing illness enrolled in a community health service in Western Sydney, 'HealthOne Mount DrUITT', have learned to negotiate the system.

The policy background to stronger patient engagement

The rhetoric of health policy is replete with calls for stronger patient engagement. The 'Expert Patient', 'Patient Engagement', and the 'Knowledgeable Patient' have all been responses to new demands on the health system (Hill, 2011; Coulter and Ellis, 2006). With the rise of the burden of chronic illness in Australia and comparable countries, health systems need to adapt and social support becomes critical.

Recent policy directions to manage the increasing burden of chronic disease in Australia have emphasised increased patient engagement in managing their health at home (National Health Priority Action Committee, 2005; National Health and Hospitals Reform Commission, 2009). Patient engagement is recognised as a central point in most chronic care models, often described under self-care, self-management programs and self-management support. Health literacy underpins patient and carer engagement and facilitates informed decision making and self-management ability (Cho, 2008; Speros, 2005; Newman, Steed and Mulligan, 2004; DeWalt, 2004).

Greater patient engagement is partly driven by governments trying to keep health systems financially viable. While that may be a persuasive argument for governments to shift the management of illness back into the community, patients and their families can also see benefits. Patients prefer to live and do as much of their dying at home as possible. Advocates of a stronger consumer and patient focus on care have also been strong backers of self-management, so long as sufficient supports have been put in place.

Furthermore, the dominant policy model of chronic illness has come under fire for perpetuating a focus on single diseases, defining the patient by one prime condition - whether heart or lung disease or diabetes - although most live with a complex mixture of co-morbidities. Conventional understandings of managing disease progression and controlling symptoms ignore the messy complexities of each human life. Supporting self-care needs to look at the bigger picture – the health challenge as part of the personal and social contexts.

What does health literacy mean?

There is much confusion in defining health literacy. Rival definitions abound, including:

Health literacy is the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions. But health literacy goes beyond the individual. It also depends upon the skills, preferences, and expectations of those health information providers: our doctors, nurses, administrators, home health workers, the media, and many others. (Institute of Medicine, 2004).

Or the emphasis can be on the application of more general functional literacy skills to health:

The knowledge and skills required to understand and use information relating to health issues such as drugs and alcohol, disease prevention and treatment, safety and accident prevention, first aid, emergencies, and staying healthy (ABS, 2008).

Different definitions lead to different approaches

These different definitions of health literacy have wider ramifications.

Should health literacy (or its lack) be seen primarily as a 'clinical risk'? For example, how much of this medical label can a patient read? How successful is their comprehension of medical instructions from their doctor? This approach leads into a top down (but often necessary) emphasis on compliance or adherence to the treatment regime. The patient is seen as a passive recipient, not an active agent. Health literacy becomes a set of individual characteristics and competencies, themselves largely by-products of education and social position. Policy prescriptions following this approach have tended to shift responsibility to individuals and the education system. This approach dominated the recommendations of the National Health and Hospitals Reform Commission (2009).

In contrast, health literacy can be seen as an empowering personal asset. It provides patients and their families with the capacity to engage confidently as independent agents with the health care system and play an active part in defining their needs (Nutbeam, 2008; Peerson and Saunders,

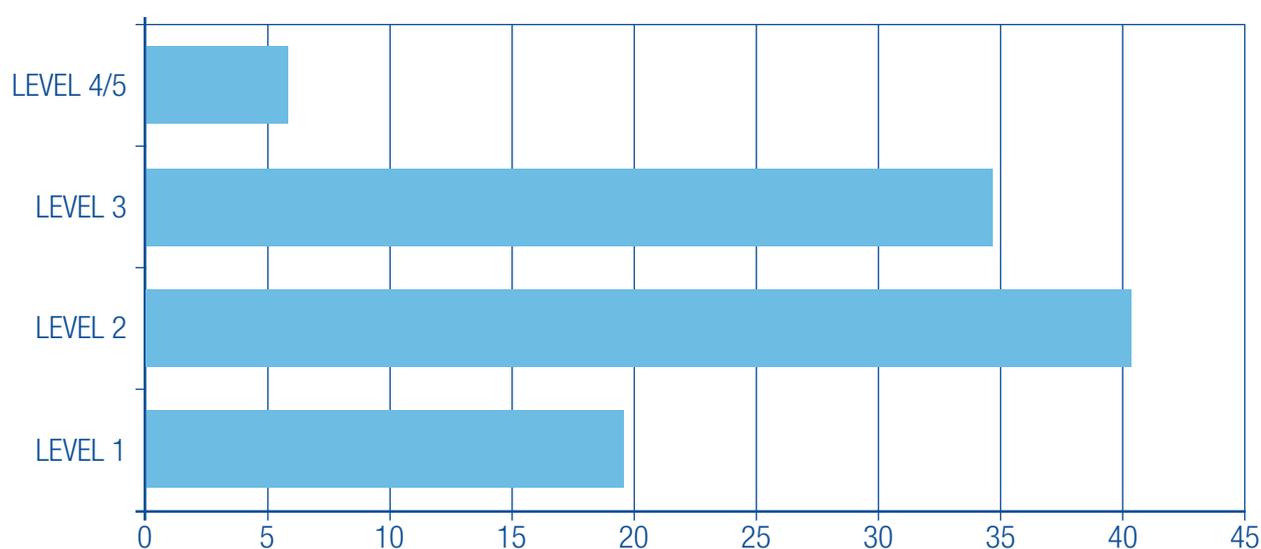
2009). Agency rather than passive understanding of information handed down by professionals becomes central. The patient is in control with 'the capacity to make a difference' (Montgomery and Little, 2011). This model of health literacy goes well beyond the individual characteristics of the patient, recognising that the support of broader community networks is crucial.

Health literacy at low levels in Australia

Health literacy in Australia is at alarmingly low levels. According to a recent survey, almost 60% of participants lacked the knowledge and skills to function at a minimal level (ABS, 2008).

The Australian Bureau of Statistics approach saw health literacy as mainly the application of general literacy to concepts, terms and basic texts. Their findings were alarming – so few Australians were in the top two quintiles that they were combined. Almost 60% were in the bottom two quintiles of health literacy skills, judged insufficient to enable an individual to function at a minimal level.

Figure 1 Levels of Functional Health Literacy in Australia, 2008.



Source: ABS Adult Literacy and Life Skills Survey 2008 (4228.0.55.002)

What this report does

How do patients and carers learn health literacy? There has been little discussion of how patients and carers learn about disease management, and how they develop their self-management abilities (Coulter and Ellis, 2007; Suhrcke, 2006). This report goes some way to filling that gap.

A qualitative study was undertaken with patients who had diabetes, chronic heart failure (CHF) and/or chronic obstructive pulmonary disease (COPD), and their carers. In this report we examine diverse elements of learning, which patients and carers identified as one of the key aspects of their experience in dealing with chronic illness. They had to learn how to manage the overwhelming uncertainty associated with living with, and caring for, a person with chronic illness.

METHODS

The study population

This report is based on interviews conducted with people living with multiple chronic illnesses in Western Sydney and the Australian Capital Territory. A second set of interviews was conducted to take the patient experience further, into particular health settings. These participants were drawn from patients enrolled in the HealthOne Mount Druitt program.

The Serious and Continuing Illness Policy and Practice Study

The Serious and Continuing Illness Policy and Practice Study (SCIPPS) aims to develop policy and health system interventions that are patient-centred and support the provision of optimal care for patients with chronic conditions.

Participants were interviewed face-to-face, and in depth. The study was approved by relevant university and health service human research ethics committees. All individuals gave informed consent prior to participating. Participants were recruited through referrals from general practices, local hospitals, community health services, specialist clinics, health care consumer organisations and Aboriginal health services. Eligible participants were patients aged between 45 and 85 with diabetes, COPD and/or CHF; and family carers with primary

responsibility for their relative's care. Fifty-two patients (male=28) and fourteen family carers (female=13) participated in the study, including seven Aboriginal patients and sixteen patients and carers from culturally and linguistically diverse (CALD) backgrounds. Most patients were older than 65 years (n=35). Forty-five patients had more than one chronic illness, with musculoskeletal conditions, diabetes and CHF being the most prevalent co-morbid conditions. Most had contact with their general practitioners (GPs) at least monthly (n=35). The average length of the illness patients had was 16.5 years (range=1- 62). The period of carer responsibility was on average 12.5 years. About half the participants (n=35) said that they currently knew enough to manage their condition.

HealthOne Mount Druitt

Participants in the second set of interviews were drawn from patients enrolled in the HealthOne Mount Druitt program. HealthOne NSW initiatives aim to increase integration and coordination of primary and community health services.

HealthOne Mount Druitt, officially opened in 2008, was the first to be established and implemented in an urban setting and is still considered to be an advanced HealthOne service in terms of implementation in a metropolitan environment and development of the corresponding model of care. HealthOne Mount Druitt is located at the Mount Druitt Community Health Centre in a purpose-built facility.

Three priority areas were identified as the focus of HealthOne Mount Druitt. They are: children, young people and their families at risk or with significant unmet needs; people with chronic and complex conditions; and disadvantaged local communities. Potential HealthOne participants are identified by GPs, community health workers, and GP liaison nurses. The linchpin of the HealthOne Mount Druitt model of care is the two GP liaison nurses who identify the patient's needs based on referrals received and assessments made and facilitate communication, case conferencing and care coordination between the various health professionals involved in the patient's care. This may be done 'virtually' without the GP or other service provider having to be physically present at the hub.

SCIPPS: voices and case studies from Western Sydney and the Australian Capital Territory

Male Patient 1 with severe COPD

He complained of difficulty breathing, complicated with chronic heart disease, "I get tight in the chest, I can't breathe, I can't get any oxygen, I can't lay down. Even now when I lay down I've got to lie on my side because I can't lie flat on my back." Difficulty walking, reliant on others for shopping for day-to-day needs.

Like many of those interviewed, he was happy with the medical services provided – though wished they were better staffed – but complained of a lack of information about his condition: "Maybe a better understanding of what goes on, but apart from that there's nothing they could improve on." He recognised a role for outside support services, but ultimately relied on the immediate care from his family:

"Health support groups and that. I suppose they could help. I don't know. I don't usually worry about them. I don't care about them really. As long as my family's there behind me that's all I worry about."

"Yeah, I want more information. I want it out a lot quicker than it is getting out. Actually, I want the stuff out on the counters quicker. For the doctors or chemists and that going to give it to you a lot quicker than what they're, what it takes them."

Male Patient 2 with emphysema

He was experiencing severe difficulty in walking up hills, and found his limited mobility 'terrible'. He had no complaints about his medical care: 'The nursing staff are great. You know they explain things to you. When I was in the ward

where ... my heart was out of rhythm, one nurse there, he was on at a night, I think he was the head nurse for the night and he come in the next morning and explained to why I was in there. He gave me a little graph, with, he said it was because it was going a few times miss a beat and he explained to me what was going on... otherwise I wouldn't have known."

Male patient 3 suffering from heart failure

He had been forced to retire early because of his heart condition. For him, the main effect of long-term illness was isolation from the social bonds of the workplace:

'I miss working, I miss colleagues, I miss male interaction' and illness meant being 'surrounded by women... And, like now the only male is you know Leo the dog.'

'Um, I'd like to get involved with, a group of people with common interests, you know, but sometimes I think it's asking for too much, you know, so you've got to keep searching. And that's what I've been doing.'

Male Patient 4 was living with COPD

"I've found out as much about it as I possibly can. I've got every bit of information I need. All I know is, is when you have COPD you haven't got much future at all and there's not much hope. And so you've just got to make the best of what you've got, with the time you've got. That's how it is. It does let you get involved in the decisions and you don't like this and you don't like that."

FINDINGS – THE SCIPPS STUDY

People living with chronic illnesses respond – and learn to manage – with different strategies. The older Australians (aged 65-85) interviewed by the SCIPPS Study described the dilemmas, especially the uncertainty that confronted them on diagnosis. They talked about the often imaginative ways they attempted to re-establish lives not completely dominated by their disease.

Facing uncertainty

Uncertainty was the most challenging aspect of chronic illness, leading to fear and anxiety (n=52). Uncertainty was often the result of people's inability to understand, identify and respond appropriately to the illness, its treatment and management, and the often unpredictable nature of the illness progression. Participants found it difficult to identify warning signs of deterioration. Their carers were uncertain about finding effective ways to look after their relative.

They felt they understood little about how the patient's ability to look after themselves would diminish the new needs for care that would develop. Carers lacked confidence in their own knowledge and skills and lacked understanding of the course of the illness, leading to confusion and anxiety.

“ It was just basically an ignorance of what he was going to need, how we were going to provide it. There's a huge gap between being in hospital and being at home ... I think that there's lots of assumptions about and around the caring role, and about the patient role, which people who have not experienced that intensity just have no perception of what it is like. ”

Patients needed emotional support, continual guidance and accessible information from health professionals – information that fitted their own learning needs, taking account of their individual contexts and stage of illness. The emotional shock of diagnosis blocked many from taking in information about their illness. They reported confusion about the changes that would be forced on their lives by the day to day management of their condition. Individuals had quite different information needs.

“ At the beginning, even if my doctor explained to me, I think the initial shock, everything went like this – over my head. No, I don't think [I have enough knowledge] ... the usual media, things like that, or the information – printed information – it doesn't really touch on those [how diabetes is managed and treated]. ”

Patients and carers had to develop new ways of learning to cope with this uncertainty – sometimes with support from the health care system, often despite its ministrations.

“ People give you a little bit of information, and the next one gives you a bit more information, and this. If I had to tell you how to skin a cow, I'd give you all the information...how to go down the front leg, how to go down the chest, how to go down...Even though you couldn't do it, you'd know how to do it. You know what I mean...all you'd have to do is to look at the information and say I'm going down the neck now. ”

Learning through formal encounters

Patients and carers described acquiring knowledge through formal educational opportunities. These included groups and programs, and direct interactions with health professionals such as doctors, nurses, physiotherapists, pharmacists, dieticians, diabetes educators, social workers, optometrists and ambulance officers. Twenty-four participants talked about their experiences with formal education sessions, such as public lectures, seminars, short courses or individual coaching. Fourteen had access to rehabilitation programs. Notably, far fewer patients with COPD (n=4/17) had been in formal education programs than patients with CHF and/or diabetes (n=20/46).

All saw formal encounters with medical and other health professionals as important in the early stage of the illness, but some had limited access to such opportunities. At one extreme, a patient recalled that his GP had prescribed treatments without telling him they were for diabetes. Nor did he make any recommendations to the patient about management.

Learning sessions with their own doctors – whether specialists or GPs – had mixed responses.

Participants described the importance of getting health professionals' explanations face to face in an environment that was unrushed, and expressed appreciation especially for those professionals who listened and displayed patience. They also talked about the importance of the health professional's empathy, not being judgmental about their situation.

Communication was often weak. Many patients were left confused about how to apply or use the information about the management of their illness. Some patients felt stigmatised by some health professionals because of their chronic illness, with feelings of rejection, guilt and blaming themselves. Their behaviours such as unhealthy diet, lack of exercise and smoking were stigmatised, leading to strong feelings of guilt, for example amongst smokers.

“ There is one specialist I can think of in particular that sort of brushed it off because I was a smoker, so you know that’s it. You were a smoker kind of thing. I mean he didn’t say it in so many words, but that’s the attitude I got. ”

Participants felt that these negative encounters with health professionals became a barrier to their learning and therapeutic relationships. They had little bargaining power, and tended to exit quietly, dropping their doctor, rather than raise confronting questions.

All of the twenty participants who had attended a formal education session that explained their illness and its management, said it was somewhat helpful in managing the illness. Patients who had attended an educational program on a regular basis for some weeks were more enthusiastic, reporting it provided an opportunity to question the application of the new strategies learnt from the program (n=10). The opportunity to practise during a formal education program was also seen as effective. The carer of a man with COPD summarized this point when she said,

“ Actually the pulmonary rehabilitation sessions have been the most useful because they also have a practical component– It’s all very well that someone comes and tells you about diet, but they don’t really factor in the fact that you have to implement it. ”

When education programs ran for a short time only, participants reported difficulty in applying and assimilating the information later, and felt abandoned to their own devices.

Language and cultural barriers compounded these problems. Patients and carers without English as their first language had to learn new ways of communicating, and also how to navigate an unfamiliar health care system. For a few patients, the language barrier had proved insurmountable, impeding effective learning and even resulting in their withdrawal from treatment and the exacerbation of potentially manageable problems.

About half of the participants mentioned some use of written materials such as pamphlets and brochures (n=30), or internet and/or media (n=16). These were all additional ad hoc methods of learning, often requiring follow-up explanations from health professionals or learning by experience to confirm their understanding. While most patients recalled receiving printed materials, they were rarely referred to as important sources of information.

A minority (n=11) did not go much beyond these formal methods of learning. They remained more passively dependent on instruction from health professionals, in particular from their doctor, and showed little interest in self-directed learning.

Learning through informal encounters

The SCIPPS patients and carers often referred to informal modes of learning. These included knowledge gained in social or casual encounters and talking to family and friends (n=37). Less formal social interactions at self-help or support group meetings organised by Diabetes Australia, Carers Australia, Australian Lung Foundation, or the National Heart Foundation were also seen as useful. Fourteen participants described how self-help or support groups had helped them develop their self-management strategies through giving them useful information that they had often not received from health professionals. In these groups, they connected with people sharing similar experiences, and learned from them. If participants found at least one benefit that suited their situation, they would continue attending the group. For example,

“ We just have a cup of coffee and talk. We try and get a guest speaker every month. Something, if we can, connected with diabetes. If not, ... what people can get to help them once they start getting older, handiwork sort of thing, ... I love meeting people, so it was just getting out and meeting people that I found that was good. ”

Participants described the importance of keeping a positive environment and making activities constructive during support group meetings, which were not necessarily directed towards learning specifically about the illness. For example,

“ My support group, we don't sit around and whinge about our illness, we get about and do stuff. We go on trips and we have lunches and that. A lot of them are a lot sicker than I am. I go to exercises, Tai Chi, I get a lot of pleasure out of that because of probably a mixture of a social content, the challenge of being able to achieve. ”

Not everyone who joined support groups had a positive experience. Patients' own attitudes toward their illness played a role in the process. It was often difficult to accept and manage the illness while believing society blamed them. Common risk factors for chronic illness such as obesity and smoking could easily be portrayed as personal character failings: the illness could have been avoided had its sufferers only led more responsible lives. These patients were particularly concerned about negative public perceptions of the chronic illness. They also found the potentially serious complications and consequences of their illness difficult to face.

A person newly diagnosed with diabetes found watching people with the same condition, but more severely impaired status, disturbing:

“ I think just having been a newly diagnosed diabetic... to be thrust in the deep end amongst amputees and people who ... obviously looked very ill. It was a bit of a jolt to the system and also I got fed up with their negative attitudes and their moaning and groaning. I thought this is not the way to handle diabetes. ”

Learning from experience

Advice from health professionals was important particularly when participants had problems implementing or practising self-care and self-management at home. However, whether learning through formal or informal encounters, patients and carers shared the dilemmas of applying their knowledge in the complexities of daily life.

Learning to manage chronic conditions occurred over time and drew on multiple sources. A shortage of information was often a problem. More often it was the difficulty of assimilating and using information. Participants often said that “it's been a learning experience over the years”, or “you learn yourself as you go along”. Nothing was simple. The complex disease conditions were often combined with the presence of co-morbidities, each requiring multiple interventions and encounters with various health and social services. This meant that developing self-management strategies and techniques was not simply a case of learning a defined set of information. Rather, the process was often complicated and continuous.

For example, a patient with chronic heart failure and diabetes complained that he found it increasingly difficult to identify low blood sugar levels because his “warning sign” had changed. He had recently been learning by trial and error to recognise this change. However, the last incident resulted in admission to the emergency department.

The information needs of patients and carers went well beyond understanding the disease process and medications or risk factors. They included learning about how to access and use the health and social security system, and how to deal with the financial impact of their chronic condition.

For many, learning was a continuous process that progressed with the disease.

“ Now you have to learn ... it is a problem and it gets continuously slowly worse and you have to cope with that and you have to change your tactic too. You cannot say I've done that and this is wonderful this year or next year and next year it might be a little bit different and you have to adjust to the situation. ”

Using fragmented and at times conflicting information for daily decision-making contributed to feelings of confusion. For example, a patient with diabetes who had seen a GP, diabetes educator, podiatrist and dietician said,

“ I learnt some stuff from those people, but I still came out puzzled in the end after all those meetings. It was still a puzzle to me and I felt I really had to go home and sort all this stuff out myself. ”

For some participants, learning was accelerated at times of health crisis. For example, a carer described how she and her husband had learned through successive crises to calculate when her husband's angina symptoms warranted a trip to the Emergency Department, what to expect if he was admitted, and how to recognise and manage signs and symptoms of deterioration.

Learning from experience - trial and error

The simplest, though sometimes most dangerous, method of learning from experience was trial and error.

Thirteen participants described 'trial and error' or 'active experimentation' as part of their learning by experience. Participants used trial and error to determine which information was applicable

or useful to their experience in managing illness. Inability to access educational resources and health professionals, either because of limited services available or not knowing about relevant services and resources, further compromised their capacity to manage chronic conditions. In the process of seeking information or looking for help, which might take a while to get, these participants experimented or tested their hunches. In trial and error, participants intentionally applied the knowledge they had to a situation in order to determine whether that knowledge was useful. These participants appeared to believe trial and error was acceptable and logical, without necessarily having their conclusion validated by health professionals.

“ I try things. I experiment with things. I know what works, I know what doesn't work. I know what the essential ingredients in managing are. ”

A participant with diabetes described how he learned to improve self-administration of insulin – a good example of the trial and error process.

“ It does hurt sometimes, but that's when I put it in, it was not quite in the right place, or you maybe held a bit of the fat too hard. You need it hard there. You put the needle in there it can hurt. Just do it softly. Just very soft. You learn yourself, you know. ”

This patient began by recognising a problem and eventually found his way (rather painfully) to a solution.

The trial and error process extended over many years. Participants described how they were still using trial and error as they negotiated various problems or situations and developed the strategies they needed to make decisions.

Learning from experience - observational and reflective learning

Learning from experience requires the development of skills in observation and reflection on changes to the body to sort out what works (and what does not). Knowledge of self-care and self-management usually started with consultations with health professionals, formal education programs, informal conversations with family and friends, written materials, internet and media and self-help support groups. However, it was only through more reflective learning that patients and carers gradually reinforced their understanding and developed the skills to manage chronic conditions.

Patients gradually developed their understanding of how chronic illness changed them. It changed them physically, with things like angina, breathlessness or high and low blood glucose levels, and changed them mentally, for example through depression. They gradually learned how all these changes affected their life. They learned to recognise dangerous signs or the limitations of their condition, and learned how to manage the triggers that resulted in them experiencing ill health. They developed decision-making skills – especially on the timing of calls for help or trust in their own ability to manage.

“ You sense it, the way I set my eye, because I get this lines coming, I don't know if there is anybody else like that or not. It's starting, getting more, and more and more so around I go and I eat something straight away, I have a biscuit or something and then again right as, minutes later, it's going, it disappears so I know what causes it. ”

“ Similarly, now I remember it, ... with the exercise walks, if, in the middle of winter, I went out in very cold weather, and I was soon to learn not to, and I walked for half an hour or so, sometimes I would feel unwell for three weeks, you know. So I stopped doing that. ”

Observational and reflective learning was found across all disease groups and cultural and linguistic backgrounds. Each person brought quite different resources into play, from prior levels of knowledge of disease and disease management, to education opportunities and indirect experience from having other members of family or friends with similar chronic conditions. When patients and carers had difficulties with communication—due to language barriers, cognitive impairment, or sight and hearing—learning took longer. Notably, when participants were anticipating a problem requiring new knowledge some said they would learn about it when an opportunity arose, and others would wait until learning was necessary.

FINDINGS - THE HEALTHONE MOUNT DRUITT PROGRAM

Health Literacy – Summary of Patient Experience

A second set of interviews was conducted to take the patient experience (revealed by SCIPPS) further, into particular health settings. These participants were drawn from patients enrolled in the HealthOne Mount Druitt program. They were interviewed about the ways in which they learned to manage their encounters with the health system. In this case, they had the support of an active network of community health workers, a GP Liaison Nurse focusing on chronic care management, and a network of GPs linked through HealthOne.

The Hospital

Overall, participants were satisfied with the care they received in hospital. When asked about their experiences with medical and nursing staff some responded with comments like “they were fantastic ... they were great”; “they were wonderful”; and a more tempered “well so far they've been pretty good.” However, some participants were dissatisfied with the care they received in hospital. Concerns included misinformation about medications and their use, or perceived short staffing leading to overly busy staff who were difficult to engage with.

Responses to questions about how well medical and other information was explained in hospital were less positive than overall comments about hospital experiences. One participant, while satisfied with the overall care received in hospital, said that she had to learn to be more assertive with hospital staff and say “Excuse me, do you want to explain what you just said” when she hadn’t understood what had been said to her. Another participant who was satisfied with care received in hospital commented that she was “the type of person to ask a question anyhow” continuing “I just won’t sit there if I don’t understand something. I’ll ask.” It appears that the more assertive and prepared a patient is to ask questions and engage with hospital staff the more likely they are to receive and be satisfied with information they receive in hospital.

Most of the other participants reported difficulties communicating with both medical and nursing staff in hospital with comments such as “they don’t explain to you properly” being common. Some participants saw this as a direct result of short staffing. As one participant explains:

“ you’d ask them and question and you wouldn’t get an answer ... but a lot of it was, short staffed ... I’m one if I go to hospital I hate ringing that bell but I’d ring the bell and six hours later somebody would poke their head about, ‘Are you okay?’. You know, I mean, so that to me has got to be short staffed. ”

Other participants got the impression it was best not to ask questions in hospital but rather to “Just do this and do that” and that communication by hospital staff was usually limited to immediate tasks required for care and/or treatment. As one participant put it, most hospital staff limited their explanations of treatment to “Oh, I’ve got to give you an injection or give you a tablet.”

While only three participants commented specifically on care received and information given by medical specialists, responses were broadly similar to how participants described hospital experiences. One carer said the specialist care received by their spouse was “really wonderful” and another said in

reference to a surgical procedure on their heart that “everything’s bloody great.” However, one man felt that his cardiologist did not explain or describe his heart condition sufficiently and in such a way that he could not fully understand and take preventive measures if possible.

General Practitioners (GPs)

Unlike hospital care, almost all participants were very satisfied with the care, treatment and information they received from their GPs. Comments included: “He’s a bloody good doctor”; “He is fantastic”; “She’s good” and “Oh yeah, love him. I’ve had lots of talks with him.”

When asked if they understood what their GP told them, or whether things were explained to them adequately by their GP, most participants responded positively. One man described how his GP took the time to explain things to him if he didn’t always understand first time around:

“ ...he just sits there and talks to you, explains things. He says, ‘Do you understand what I’m talking about?’. I said, ‘Ah’, I said, ‘a little bit’, you know, but he said, ‘What don’t you understand?’ and I tell him and he explains it again. ”

One woman appreciated the practical advice her GP gave her about dealing with, at times, life-threatening chronic illness:

“ ... my local doctor, ...I got upset when I come home from hospital one of the times when they were talking about you know you might die, and I said to her, she said well I’ve got serious problems you know and she said just take everything as it comes you know she said if you can get along by not doing anything she said don’t do anything, she said and just take one day at a time and make short term goals she said, don’t try and make a couple of years down the track or something, she said just go from birthday to Mother’s Day to ... you know. ”

Other participants described their close relationships with their GPs and how this made a difference to the care they received. One woman explained how her GP knew her well enough to get to the bottom of why she was visiting him:

“ ... like a few months ago I was depressed, I really was. He (GP) said, ‘What’s wrong?’ I said, ‘Nothing. I feel great.’ He goes, ‘No’, he said, ‘You’re depressed over something.’ ”

Another woman described how her long and close relationship with her GP helped when she was diagnosed with cancer:

“ Yeah well when they found the cancer... I walked in, they rang me and said you’ve got to come here. And I had – I knew something was wrong. I walked into his surgery and he doesn’t, and there’s people there, and I always get embarrassed because he lets me in, and he just gave me a big cuddle and everything and I said ‘It’s cancer isn’t it?’ and he said ‘Yeah.’ Yeah. Because I’ve been with him for 25 years ... He’s seen me and at my best at my worst, everything. ”

Other participants liked the fact that their close relationship with their GPs meant they would do house calls or keep an eye on them in hospital:

“ He actually popped down to the hospital to see me. Just dropped in and out ... He’s dropped in here (participant’s home) ... Knocks on the doors, doesn’t charge anything. ‘How’re you feeling mate? I was driving past and thought I’d pull up and see if you’re alright’ ... If I could have him and the team down here (Mount Druitt Community Health), I wouldn’t need anybody else [laughter]. ”

Community Health

As with care received from GPs, participants were very satisfied with the care, treatment and information they received from Community Health services. In particular, participants commented on the value they placed on the way community health staff explained aspects of their care and treatment in straightforward ‘truthful’ ways. As one man put it:

“ They’re talking true it was true, everything, I know that ”

Others echoed this sentiment. Another man explained why he was satisfied with community health staff when he was asked about his interactions with them in his home:

“ ... you know just by talking and explaining things to me afterwards, I can’t really write real good, you know, and they explain things to me ... about your bloody pain and different things, you know, when I get out of hospital and all sorts of stuff and they come and see me, see how I’m going and all that sort of stuff. ”

One man valued the ongoing contact and continuity of care he received from community health services, and also community health staff’s ability to translate and clarify medical information.

For one woman, it was community health staff’s ability to listen that was important:

“ Yeah yeah I think they’re wonderful. They’re very nice women, girls. They listen to you – they don’t want to just sit there and chatter, they want to talk about, you know, about me type of thing and how I’m feeling. I can’t fault them at all. ”

When asked how receiving community health services had changed things for her she continued that knowing they were close and easily contactable gave her a sense of security:

“ Knowing that they’re around. [laugh] Yeah. Security. I’ve got phone numbers for them, they’re nice and close...and if I did need them, like if I needed [community health staff member] I can ring her or, you know, down at the health place. They’re there for me, yeah and it’s what the security is yeah and they’ll do anything in the world for you, they’re good. ”

Another woman said she had learned to ask for help and information when she needed it because of her interactions with receptive community health staff:

“ I’ve sort of got to learn sometimes to ask for help, that’s where my problem is ... I get, I think I get embarrassed and just finding out things. ”

She also valued community health staff’s ability to do home visits:

“ And by having the community nurses, if you’re unwell they will arrange and they can come to the house so you don’t have to panic and get up and get dressed. ”

One participant with both chronic illness and mental health issues explained how much she valued community health services’ broad and holistic model of care that took account of physical, mental health and wider social support:

“ So yeah ... they’ve done like a lot for me like if I didn’t have the help I wouldn’t have the grass done and the walker, I wouldn’t be talking about my problems, I probably would’ve had a heart attack by now you know like and like they’ve ... helped me out a lot [community health staff member] was the first one and she ... helped me talk to, get a physiotherapist ... [community health staff member] started the ball rolling you know and like helped me with the physio and the psychologist and you know like otherwise you know I probably would’ve had a nervous breakdown by now ... ”

Medication

Most participants had their daily medications organised into morning, midday, afternoon and/or evening doses using either their own containers or blister/Webster packs available from pharmacies. Most, but not all, participants knew their medications and what medication related to what symptom or illness. Some talked of being confused about medications in the early days or years of their illnesses but most said that they soon became familiar with medications and their effects as they learned to live with their chronic conditions. While it is hard to judge whether participants adhered to medication regimes, one woman noted that her GP had told her that if she didn’t take her pills she would die and that this was a very good motivator to remain compliant.

Information/Mobile Technology

Out of all participants asked only one carer/spouse had a computer and used it to access medical and medications information. More participants had mobile phones but only one person knew how to text and was interested in receiving medical and appointment information by text.

Others commented that they might be able to use computers and mobile phones if they had someone living with them (for example, a son or daughter or grandchild) to not only show them how to use the technology but, equally importantly, to remind them how to use it when they forgot through lack of frequent use.

Community approaches to health literacy

The patients and their medical carers interviewed at HealthOne Mount Druitt stressed the importance and responsibility of local communities in enabling patients to manage their illness.

The health care providers emphasised early patient education programs:

“ You are influencing their attitudes at an early level and helping them to become more thoughtful so that they think that is where they need the support, and the ground(ing) so that they don't feel like they are on shifting sand all the time so that they – the healthcare team has provided them with resources, with education, and with the support that is needed so that they feel like they have got a good plan, that they are not landing in the middle of a grand final without a plan therefore they go to accident emergency. ”

“ Certainly a lot of people with chronic lung disease in the age group go to hospital because they're anxious, not because of their chronic lung disease. Well, I mean what makes the difference between going to hospital is not the disease, it's the anxiety. So it ought to be in theory possible to cocoon them with care in the community, so that the security they get from being in hospital they can get at home. And I'd like to think that ...one of HealthOne's missions is at ... that end of the spectrum. ”

Conclusion

The report examined health literacy in seniors with chronic illness. It looked at how patients and carers learn about disease management, and how they develop their self-management abilities and learn to navigate complex health systems. It conveyed the patient and carer experience of managing chronic disease.

One of the consistent findings of the interviews was a sense of bewilderment and uncertainty amongst patients and their carers. After serious episodes, often requiring repeated hospitalisation, they had been left largely to their own resources to cope with the challenges.

The SCIPPS data was coded to enable the study of our subjects' coping strategies and the development of a knowledge base of their illness. Patients and carers learned how to manage their illnesses through a variety of processes.

Health literacy is increasingly seen as an essential element of any effective self-management program. Recent work has pushed the concept beyond simple notions of a desirable quantum of knowledge dispensed by health professionals, and the study of the communication strategies that enable patients to assimilate and apply this basic information.

Broader notions start from notions of self-efficacy: the ability of individuals to apply knowledge to new circumstances, to navigate the health system and adopt active learning strategies. These debates have still tended to focus on an end state – the sum of an individual's knowledge and resources. They say little about the process by which these are acquired: active learning strategies involving broader family, friend and other social networks and support groups that can facilitate learning and reinforce self-management techniques. HealthOne provides a limited version of this wider support, but at times also helps and supports the wider family and carer networks of an individual with chronic illnesses.

Health literacy becomes a community or societal asset – moving well beyond those already ill to build the next layer of support. This includes reinforcing early prevention messages in schools and other educational and work place settings (Nutbeam, 2008; Peerson and Saunders, 2009).

This learning process provided one of the most striking themes of the SCIPPS interviews. The analysis revealed a set of parallel learning strategies, ranging from formal encounters with the health system, informal learning contexts, such as support groups, and a broad category of 'experiential learning'. Most patients referred to 'trial and error' as the most common form of learning – sometimes this drew on other forms of learning with some success, in others there were more worrying results from blind experimentation.

Some clear policy directions emerge. Health literacy is often seen as a one-off educational process, a transfer of skills from health professionals to patients. Effective self-management strategies will have to incorporate a stronger sense of adult learning strategies, and incorporate trial and error and continuous learning.

There is much work to be done in improving health literacy in seniors with chronic illness. While this study is an important first step, "the importance of health literacy has been acknowledged but the agenda remains largely un-owned and uncoordinated" (Saunders, 2011).

REFERENCES

- Australian Bureau of Statistics, (2008). Adult Literacy and Life Skills Survey 2008 (Cat. No. 4228.0.55.002).
- Cho, Y.I., et al. (2008). Effects of health literacy on health status and health service utilization amongst the elderly. *Social Science & Medicine*, 66, 1809-1816.
- Coulter, A. and Ellins, J. (2007). Effectiveness of strategies for informing, educating, and involving patients. *British Medical Journal*, 335, 24-27.
- Coulter, A. and Ellins, J. (2006). *Patients-focused intervention: A review of the evidence*. London: The Health Foundation
- DeWalt, D.A., et al. (2004). Literacy and Health Outcomes. *Journal of General Internal Medicine*, 19 (12), 1228-1239.
- Hill, S. ed. (2011). *The Knowledgeable Patient: Communication and participation in health*, Wiley-Blackwell/ Cochrane Collaboration.
- Institute of Medicine, (2004). *Committee on Health Literacy Report*. USA.
- Montgomery, K. and Little, M., (2011). Enriching patient-centred care in serious illness: A focus on patients' experiences of agency. *Milbank Quarterly*, 89, 381-398.
- National Health and Hospitals Reform Commission, (2009). *A Healthier Future for All Australians: Final Report*. Canberra.
- National Health Priority Action Committee, (2005). *National Chronic Disease Strategy*. Australian Government Department of Health and Ageing, Canberra.
- Newman, S., Steed, L., and Mulligan, K. (2004). Self-management interventions for chronic illness. *Lancet*, 364 (9444), 1523-37.
- Nutbeam, D., (2008). The evolving concept of health literacy. *Social Science & Medicine*, 67 (12), 2072-2078.
- Peerson A. and Saunders M. (2009). Health literacy revisited: what do we mean and why does it matter? *Health Promotion International*, 24 (3), 285-296.
- Saunders, M, crikey.com.au/croakey/2011/07/29/tackling-the-health-issues-left-in-the-too-hard-basket-what-can-we-learn-from-the-us/
- Speros, C. (2005). Health literacy: concept analysis. *Journal of Advanced Nursing*, 50 (6), 633-640.
- Suhrcke, M., et al. (2006). *Chronic disease: An economic perspective*. Oxford Health Alliance: London.

ABOUT THE NATIONAL SENIORS PRODUCTIVE AGEING CENTRE

The National Seniors Productive Ageing Centre is an initiative of National Seniors Australia and the Department of Health and Ageing to advance research into issues of productive ageing. The Centre's aim is to advance knowledge and understanding of all aspects of productive ageing to improve the quality of life of people aged 50 and over.

The Centre's key objectives are to:

- Support quality consumer oriented research informed by the experience of people aged 50 and over;
- Inform Government, business and the community on productive ageing across the life course;
- Raise awareness of research findings which are useful for mature age people; and
- Be a leading centre for research, education and information on productive ageing in Australia.

For more information about the Productive Ageing Centre visit www.productiveageing.com.au or call 02 6230 4588.



23 Torrens Street, Braddon, ACT 2612 **P 02 6230 4588** **F 02 6230 4277**
E info@productiveageing.com.au **W www.productiveageing.com.au**