

**Supporting health literacy and self care decision  
making for people with chronic illness**

**A review of the literature**

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## **CONTENTS**

CONTENTS .....	3
INTRODUCTION .....	4
AIMS .....	6
METHODOLOGY.....	6
APPRAISAL OF LITERATURE.....	7
WHAT IS MEANT BY 'SELF CARE'?.....	9
HEALTH LITERACY.....	15
THE ASSOCIATION BETWEEN HEALTH LITERACY AND SELF CARE OUTCOMES .....	18
SELF EFFICACY .....	24
THE RELATIONSHIP WITH THE HEALTHCARE PROVIDER .....	29
PEER SUPPORT AND SUPPORT NETWORKS.....	38
DISCUSSION .....	40
CONCLUSION .....	44
REFERENCES .....	46

## **INTRODUCTION**

Chronic diseases are those that are long-lasting with persistent symptoms. The incidence and prevalence of chronic disease is a major health concern in Australia and other developed countries, placing significant burden on individuals, communities, health and economy. Chronic diseases have not always had a dominant impact on health, with infectious diseases and injury being more prevalent until the middle of the twentieth century. The control of infectious diseases in addition to changes to demographic factors and living and working conditions, and increases in the prevalence of risk factors, have seen chronic diseases grow in importance over the last three decades (Australian Institute of Health and Welfare (AIHW), 2006).

Health risks associated with lifestyle and the environment such as tobacco smoking, diet high in fat and sugar, excess alcohol use, physical inactivity, excess weight, and air pollution has resulted in Australia facing an epidemic of chronic illness (Peterson *et al.*, 2004; AIHW, 2006). Based on self reporting, the AIHW estimated that between 2004-2005, 77% of the Australian population had one or more long term health conditions (which had lasted or was expected to last for at least six months) (AIHW, 2006). There is widespread recognition of the inadequacy of the acute care health sector in managing the health of people living with long term medical conditions. This is particularly the case for people who live with chronic comorbid conditions and undiagnosed symptoms (Williams, 2004; Kralik, 2005; Peterson *et al.*, 2004; Bayliss *et al.*, 2003). The incidence and prevalence of chronic disease is posing an enormous challenge to the health sector. Increasingly, governments pressured by diminishing resources are tackling chronic

disease management with a shift away from the traditional medical system toward primary health care strategies, and particularly self care or self management. This trend places a new emphasis on the person. People with chronic illness are no longer considered to be “passive recipients of care’ but rather the principle decision makers in their care (Bodenheimer *et al.*, 2002).

There is recognition in the literature of the important role that health professionals play when supporting people to develop self care knowledge and skills. There is also acknowledgement of the need to move away from past notions of the healthcare relationship where the provider was seen as ‘expert’ and the person as ‘passive’. The literature however, is less informative about fundamental ways of supporting people to negotiate and navigate a pathway through the overwhelming mass of sometimes conflicting information, interests, priorities and perspectives of both the medical system and the individual’s lifestyle. Although causal relationships between limited health literacy and health outcomes are not firmly established, cumulative and consistent findings suggest there may be a connection. How can health literacy be enhanced? How can the person be supported to arrive at a point where meaningful self care decisions can be made, offering both a degree of control over illness without compromising well being? The authors recognise that this may be the most challenging aspect of self care decision making. What helps or hinders this complex process? What kinds of experiences support people to move toward being ready to participate in self care? How do healthcare workers recognise when people are at this point? The answers to these questions will equip healthcare workers with an understanding about useful ways to provide self care support

that recognise the complex multifaceted nature of the individual's response to living with chronic illness and the overwhelming complex demands made by self care.

## **AIMS**

The aim of this review is to examine the chronic illness and healthcare literature in order to provide answers to the following questions:

- What enables and/or constrains the integration of biomedical and social understandings of the body and disease in the decision making and self-care practices of people living with chronic conditions?
- What can trigger critical turning points for people living with chronic conditions to move towards positive pathways in self care decision-making?
- How do health professionals recognise readiness to self-care in a person living with chronic condition(s)?

## **METHODOLOGY**

The literature relating to self care and health literacy in both the international and Australian context was sought with particular focus on the issues raised by the three questions, these being health literacy, readiness to change, and triggers for readiness to change. Selection of the literature was guided by the following criteria:

- published in English
- relevance to the research topic and questions
- published between 1996 and 2006 but also including some specific studies and seminal works from previous years.

The search strategy included using seven electronic databases, these being: Google Scholar, Google, CINAHL fulltext, Medline, Medscape, Cochrane Database, and Dogpile. The initial search terms and phrases used were: 'self care'; 'chronic illness'; 'health literacy', 'health professionals' and 'readiness to change'. Different variations of these terms and phrases were used. More specific keywords and phrases were used in the latter phase of the literature search. Scrutinizing the reference lists of publications to identify key texts and authors extended the search. The search yielded 145 publications that were considered to be relevant to the subject area. Of these 95 publications were considered directly relevant to the aims of the review.

## **APPRAISAL OF LITERATURE**

There is a much greater proportion of the literature relating to self management than there is self care. Since the term self management is often used interchangeably with self care, articles relating to self management have been included in this review. A recent, small body of literature which emphasizes the person's experience of chronic illness focuses on self care as being different from self management. With increasing recognition of self care and self management as an effective means of managing chronic illness much research has focused on identifying the factors that enable or constrain self care. A large proportion of this has been conducted in the field of psychology and firmly locates self efficacy as pivotal to the readiness and ability to engage in the behaviours associated with self care. Self efficacy has been the focus of much research in the area of arthritis self management. There is a significant and growing body of medical and nursing literature which points to healthcare relationship as a critical factor in enabling or constraining

aspects of self care. This literature recognizes the need to move away from traditional notions of the healthcare relationship toward a person centred partnership which recognizes the person's expertise and autonomy. The association between health literacy and self care is a relatively recent theme in the healthcare literature, and as yet still a relatively unexplored factor in self care. However it looms as having a major impact on health outcomes for people living with chronic illness. Peer support was well recognized in the literature during the 90's as having important benefits for people learning to live with chronic illness, particularly in the context of self management programs. However there is a gap in the literature of research which seeks to identify whether it helps or hinders the process of making sense of medical information in the context of day to day life. The most illuminating understandings about self care are found in qualitative research which explores the person's perspective, a methodology which is increasingly favoured in the chronic illness literature.

Of the 95 articles referred to in the review most were written in the United States of America. A smaller number of articles (approx 25%) were written in the United Kingdom, Canada or Australia. Two articles were written in Germany and Holland. The majority of articles were research based, with approximately 30% being qualitative studies and approximately 30% being quantitative studies. Two of the quantitative studies were random controlled trials. All studies selected were of high research standard with comprehensive reporting of the research population, methodology and research tools used. The population numbers reported varied greatly ranging from 12 to 26,091. The smaller populations were largely associated with qualitative research while the larger

numbers related to quantitative research. A few of these were the results of national surveys and involved large samples of the population. Over 30% of the articles were based on expert opinion, these being selected on the basis of established authorship in the topic areas, government studies and information sources and individuals and institutions who have credibility in the topic areas.

### **WHAT IS MEANT BY 'SELF CARE'?**

The language relating to self care in the literature is confusing because of a lack of definition. Self care is interpreted in different ways by authors, policy makers, and diverse health professionals within different disciplines. Frequently both of the terms 'self care' and 'self management' are used interchangeably within the same article, as though their meaning was the same. Indeed it is sometimes difficult to distinguish any difference between the two concepts. However there is a small body of literature which recognises that self care is different from self management and advocates for a different conceptualisation of self care management (Paterson *et al.*, 2001).

Definitions of self care are problematic since they vary according to the understanding of the author or the particular discipline referred to. For the purposes of this review, we adopt the advice of Paterson *et al.*, (2001) who suggests that practitioners view every day self care decision making "as personally constructed, changing over time and in various situations entailing a complex interplay of mediating and contextual influences and arising from an authoritative knowledge that evolves in living with the disease over time" (Paterson *et al.*, 2001:p.340). Drawing on the work of others (Pincus *et al.*, 1998; Von

Korff *et al.*, 1997), Thorne *et al.*, (2000:p.82) conclude that self care “refers to the full range of activities that persons with chronic illness may engage in to promote their health, augment their physical, social or emotional resources, and prevent adverse sequelae from their disease”. Self care in the context of chronic illness has received some attention in research but is still a relatively under explored concept in health research (Meetoo, 2004).

Self management programs have been studied widely with particular focus on effectiveness (Bodenheimer *et al.*, 2002). Definitions of self management are also problematic; however there appears to be stronger consistency of meaning. Typically, self management is associated with formal education, knowledge and skill development and compliance or adherence to a prescribed medical regimen (Thorne *et al.*, 2000). Redman (2005:p.4) defines self management preparation as referring to “the training that people with chronic health conditions need to be able to deal with taking medicine and maintaining therapeutic regimes, maintaining everyday life such as employment and family, and dealing with the future, including life plans and the frustration anger, and depression”. The Expert Patient Approach uses the term self management to mean “any formalized patient education programme, aimed at providing the patient with the information and skills necessary to manage their condition within the parameters of the medical regime” (Department of Health, 2000). Generally, self management is a more structured learning experience than self care and it includes a focus on ways people can comply or adhere to a prescribed medical regime. Self management would therefore seem to reflect more of a biomedical perspective.

## **Self care in everyday life**

Paterson *et al.*, (2001) problematises current understandings of self care which rely upon the concepts of patient compliance to a prescribed medical regime and that view self care as a series of rational, once off decisions. In contrast, these authors focus on the individualised fluid nature of self care decision making and behaviours in everyday life. Thorne *et al.*, (2003) emphasise the uniqueness and complexity of self care decisions. On the basis of qualitative research with people with significant experience of self care Thorne *et al.*, (2003) conclude that everyday self care decision making is “a complex developmental process that takes place within the context of a disease trajectory, a healthcare culture and a uniquely meaningful life. It involves assuming control of self care management, fine tuning the basis on which self care decisions should be made, and coming to a complex understanding of how to judge the quality of these decisions in light of meaningful outcomes” (Thorne *et al.*, 2003:p.1349). All of this happens repeatedly in the course of a person’s everyday life.

Simply put, self care requires the person making a conscious decision to take control in shaping the illness journey. In negotiating life with chronic illness every day, the person learns through processes of adjusting and modifying dosages and treatment to accommodate individualised priorities for life. This dynamic process and experience of trial and error, self monitoring and evaluating of one’s decisions equips the person with unique, experiential knowledge and wisdom about living life with chronic illness.

Self care has been described by people living with chronic illness as being entwined with

a sense of 'being' and 'becoming' (Kralik *et al.*, 2004a). The experience and familiarity of self care over time leads to quick and subconscious responses by the person in the context of routine life. When the inevitable unfamiliar experiences such as being in new environments, changes in the course of a disease or new aggravations occur, self care decision making becomes more conscious and deliberate. It is important to say that when we refer to experience gathered as a result of problem solving and fine tuning self care practices we are not referring to the experience of every day life as lived by any person. This type of experience is different; precisely because it is an accumulation of wisdom and learning from being faced with a particular reality, the struggles of living with an illness day to day.

Learning to self care is inevitable, given that the person experiences day to day management of chronic illness in the absence of health professionals (Bodenheimer *et al.*, 2002). But day to day self care is by no means straightforward. It can be a formidable prospect with many hurdles to overcome. It may be perceived by the individual as yet another burden, particularly in the early phase of adjusting to diagnosis (Kralik *et al.*, 2001). Typically people are bombarded with a mass of complex and unfamiliar medical information, instruction and expectations about managing their health (Kralik *et al.*, 2001). This has to be weighed up against what the person's own intuitive sense of what works best for them and their own learned principles of self care (Thorne *et al.*, 2003). Self care places considerable and sometimes unfamiliar demands on the person (Cutilli, 2005; McCray, 2004) not only when navigating through the deluge of information, but also in adjusting to the demands of everyday decisions and behaviours necessary to

maintain optimal health and avoid adverse sequelae. Along with this, there is a requirement to navigate a complex healthcare system and relate to a range of healthcare providers. For many people this means developing new knowledge and skills and dealing with unfamiliar tasks, a significant ask when they are already adjusting to the reality of living with a chronic condition.

### **Barriers to self care**

Orem's self care deficit theory of nursing identifies three sets of limitations for self care, these being the limitations of knowing, limitations of judgement and decision making and limitations of restriction on result achieving courses of actions (Orem, 1991). Whilst some of these are reflected in the responses of people living with chronic illness when identifying barriers to self care, the reviewer concludes that Orem's theory of limitations fails to describe the complexity of the barriers people typically face as a result of the wider context of their lives. Snoek (2002) writes about the barriers to diabetes self management and points to factors in the psychosocial context of the person's life such as the role of attitudes and illness beliefs as determinants of behaviour, relational conflicts, lack of social support, financial barriers, poor access to healthcare. Snoek (2002) advocates for genuinely attempting to understand the person's perspective to enable healthcare providers to communicate more effectively with the person and to tailor self care intervention to their needs.

Glasgow *et al.*, (2003) suggest that identifying barriers to self care is important at the outset of a self management program, a point that is also made by Wagner *et al.*, (2001).

A number of qualitative studies have focused on barriers to self care for people living with a single chronic condition (Leenerts, 1998; Simmons *et al.*, 2004 (online); Lansbury, 2000; Riegel *et al.*, 2002; Schoenberg *et al.*, 2001). Multiple barriers to self care have been reported such as gaps in knowledge, physical and economic access to care, effects of medications, negative emotions, and personal difficulties in changing lifestyle.

Bayliss, *et al.*, (2003) conducted qualitative research with people living with two or more chronic medical conditions to identify perceived barriers to self care that are associated with co-morbidity. The barriers identified by people living with chronic illnesses included physical limitations, the combined effect of conditions, compound effect of medication, side effect of medication, knowledge deficits about the conditions, economic constraints, low self efficacy or loss of control, emotional impact, inadequate communication with providers, logistical issues, need for or use of social support and the burden of a dominant disease. Evident among these barriers is the effects of the competing demands that co-morbid conditions place on the person. The compound effect of conditions and the burden of multiple medications make self care an even more complex and overwhelming prospect. Bayliss *et al.*, (2003) conclude that single disease models of self care may need to be modified to accommodate the various issues associated with co-morbidity. They suggest that a reorganised model which emphasises collaborative management of physical and emotional well being may alleviate competing demands. The conclusions of this research are that people with co-morbid conditions experience additional barriers to self care associated with having more than one condition. Hence models of self care based on a single disease may be inappropriate for

these people (Bayliss *et al.*, 2003).

After examining self care and the potential barriers to it as defined by people living with chronic illness, it is important to examine a number of issues which are positioned in the literature as key factors in the ability to self care. These issues contribute to understandings that inform the responses to the questions that guide this review. The literature identifies health literacy, self efficacy, the nature of the healthcare relationship, and social networks as key factors in the ability to self care.

## **HEALTH LITERACY**

Health literacy is viewed as a currency for negotiating the health care system (Parker *et al.*, 1999). It is a complex phenomenon that involves and is shaped by individuals, families, communities and wider systems. Poor health literacy may affect the health of many Australians through incapacity to make self care decisions and impact on the ability of the health care providers to provide effective care. Research findings report a causal relationship between limited health literacy and poor health outcomes (Nielsen-Bolman *et al.*, 2004; Rudd *et al.*, 2004). People are not equal in their ability or capacity to take on new roles of seeking information, understanding of health issues, being aware of rights and responsibilities, and acting in the interests of their health (Nielsen-Bolman *et al.*, 2004). Poor health literacy is common. In America, the National Adult Literacy Survey (NALS) reported that one quarter of the adult population have low functional literacy skills (Parker *et al.*, 2003; Kirsch *et al.*, 1993). Poor health literacy is particularly common among the older population, people living in poverty, those who experience

language barriers, low educational standard and social disadvantage (Parker *et al.*, 2003; Parker *et al.*, 2001; Wilson, 2003; Porr *et al.*, 2006; McCray, 2004).

### **What is Health Literacy?**

Health literacy is more than reading, writing and numeracy (Nielsen-Bolman *et al.*, 2004; Parker *et al.*, 2003; Cutilli, 2005; McCray, 2004). Aspects of health literacy include the power of spoken and on line communication, the impact of understanding science and media, cultural understandings and differences in the way people make meaning of health information.

Health literacy has been defined as “The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” (Health People 2010, Accessed 28 December 2006).

Health literacy involves listening, reading, speaking writing and mathematical skills that may not be related to education level achieved (Murphy *et al.*, 2000).

People who have an adequate level of health literacy are able to understand and critique both oral and written information about their health, can follow written and numerical directions regarding diagnostic tests and therapeutic regimens, can ask pertinent questions of healthcare workers, can report facts in relation to prior conditions and treatments and can solve problems in the course of every day care (Parker *et al.*, 2001; Parker *et al.*, 2003; Cutilli, 2005). A health literate person is able to use health concepts and

information and generalise it to new situations. They are able to participate in ongoing public and private dialogues relating to health, medicine, scientific knowledge and cultural beliefs. At the advanced end of health literacy, people are able to take action at a social, individual and community level in the interest of their own health (Zarcadoolas *et al.*, 2005; Parker *et al.*, 2001; Parker *et al.*, 2003; McCray, 2004).

Nutbeam (2000) conceptualises health literacy in its broadest sense and recognises its relationship to social, economic and structural barriers to health. He presents a classification of health literacy over three levels which denotes progressive levels of personal empowerment and autonomy along with greater capacity to act in the interests of one's health.

- **Basic/Functional literacy**

Enough basic skills in reading and writing to be able to function effectively in every day situations (a narrow definition of health literacy)

- **Communicative/interactive literacy**

More advanced cognitive and literacy skills which along with social skills enable participation in everyday activities, extraction of information and making meaning from different types of communication and application of new information to changing circumstances.

- **Critical Literacy**

More advanced cognitive which along with social skills enables critical analysis of information and the use of this information to affect life events and situations (exert greater control with regard to health)

These levels of literacy are reflected in the broad definition of health literacy suggested by the World Health Organisation (Nutbeam, 1998:p.294)

Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health.

Health literacy means more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively health literacy is critical to empowerment".

## **THE ASSOCIATION BETWEEN HEALTH LITERACY AND SELF CARE OUTCOMES**

People with inadequate health literacy have been found to have poorer health outcomes (Nielsen-Bolman *et al.*, 2004; Rudd *et al.*, 2004). They report a poorer health status and have limited understanding about medical conditions and treatments along with increased risk of hospitalisation (Council on Scientific Affairs (Ad Hoc Committee on Health Literacy), 1999). It is reasonable to assume then that people living with long term medical conditions and limited health literacy would also have poorer health outcomes.

### **Health literacy interventions**

Previous studies have sought to examine the association between health literacy and diabetic outcomes among people with Type 2 Diabetes in the primary care setting (Kim

*et al.*, 2004; Gerber *et al.*, 2005; Schillinger *et al.*, 2002). Poor health literacy was found to be independently associated with poorer glycaemic control and higher rates of retinopathy. Schillinger *et al.*, (2002) concluded that inadequate health literacy might account for the disproportionate burden of diabetes related complications among disadvantaged populations. Kim *et al.*, (2004) demonstrated that self management capacity improved once people with diabetes received appropriate diabetes education. Other research of this nature has focused on asthma self management. Williams *et al.*, (1998) found that inadequate literacy was strongly correlated with poorer knowledge about asthma and improper use of the metered dose inhaler that is essential to effective control of asthma. Kalichman *et al.*, (1999) researched with HIV sero-positive men and women to study the significance of health literacy in relation to other predictors of adherence to treatment. They found that health literacy was a significant and independent predictor of 2 day treatment adherence after controlling for age, ethnicity, income, symptoms, substance abuse, social support, emotional distress and attitudes toward healthcare providers. Evidence however, supports the notion that focused intervention can improve health literacy and comprehension and short term behaviour change for chronic disease management skills such as short term medication administration and preventative screenings (Gerber *et al.*, 2005; Kim *et al.*, 2004; Kalichman *et al.*, 2005). Health literacy interventions that targeted more complex health behaviours such as modifying dietary practices and exercise regimes were less successful over a longer period of time. Only one study conducted by Davis *et al.*, (1998) measured sustained longer term behaviour change in relation to vaccination administration over a six month period and the findings revealed that sustained behaviour change following focused

health literacy intervention did not occur. Comprehension only of written resources however may not lead to sustained behaviour change (Wydra, 2001). Combined approaches to improving health literacy such as frequent educational counselling sessions, low-literate written information, visual and audio strategies have proved most effective. The authors of these studies call for healthcare professionals to take responsibility for creating supportive, culturally sensitive environments in regards to promoting literacy, to modify practices and employ strategies to improve communication with people with poor health literacy.

### **Why recognition of health literacy might be difficult.**

Often referred to as the ‘silent epidemic’ people are embarrassed or ashamed of inadequate health literacy and do not disclose the problem to healthcare workers (Erlen, 2004; Parker *et al.*, 2001; Parker, 2000; Parker *et al.*, 2003; Cutilli, 2005; McCray, 2004). Consequently health professionals may not recognise poor literacy. It can go unnoticed and ultimately impacts negatively on health outcomes. People become adept at keeping low literacy hidden using reasoning such as ‘I left my glasses at home’, or ‘I have a headache now, I will read it later’. Low literacy skills are reported to be correlated with poorer health outcomes, less compliance with medical instruction, less likelihood of seeking care early, and increased periods of hospitalisation (Mayer *et al.*, 2004; Schillinger *et al.*, 2002; Parker *et al.*, 2001; Cutilli, 2005; McCray, 2004).

## **Information needs and Health Literacy**

Timmins (2006) explores the concept of 'information need' and cites Rodgers description of the term as a want or desire for information to be shared by professionals using appropriate communication skills. Information seeking behaviour is seen to be a response to a challenging or threatening situation such as a health issue. Wathen *et al.*, (2006) in their research of the information needs of women living in rural areas suggest that as healthcare providers increasingly expect people to take responsibility for their healthcare there is a growing demand for high quality, timely and useful health information. They stress the importance of understanding the needs of users and the role of information systems and healthcare professionals as part of the delivery system. Information will not be empowering in self care decision making unless it is accessible to the person. Those with adequate health literacy skills will be at a distinct advantage. A strong theme in the findings was the lack of time given by physicians to frame information appropriately. Methods of communication such as websites and telephone triage that adhered to strict protocols were less well used and liked by rural women. A strong finding of this study is the important role of health information intermediaries in the information seeking process. Indications are that when validation, comfort and support were associated with health information intermediaries this acted as an enabler for the women participants.

In earlier work, Wikblad (1991) examined how people perceived the information provided to them by health professionals about self care management of diabetes. Information in and of itself was found to be inadequate. Rather, people had to understand

how to use that information and what resource implications using it had. People found that information provided only once was not sufficient. The communication of the health professional delivering information was vital. These research findings confirm that information needs go beyond the act of providing of information to include creating a supportive environment for exploring what the information means in the context of the person's life and how it can be applied. It also involves providing validation and a comfortable space for the person to process the information without feeling diminished for requiring that level of support.

### **Strategies for enhancing Health Literacy**

Health literacy is critical to the complex skills associated with self care. When health literacy has been addressed in the context of chronic illness, better outcomes are likely (Schillinger *et al.*, 2002; Parker *et al.*, 2003). Cutilli (2005) suggests that having access to appropriate written materials is not enough. Healthcare professionals need to assist people to problem solve the best ways for them to understand health information and get what they need from the healthcare system. In terms of strategies to address low health literacy, the call is made for health care settings to become 'shame free environments' where people feel comfortable to seek help without feeling stigmatised. This needs to be a culture where people are offered assistance routinely with forms and information. Strategies include having available non written material to convey health messages, including picture books, videotapes, audiotapes and multimedia presentations. It is suggested that any written material be at fifth grade level or lower (Parker, 2000). Healthcare workers are advised to adjust their communication to meet the needs of the

person e.g. use simple language, slow down and include family members in the discussion. Breaking information down into small relevant blocks will also aid the person with low health literacy. Adopting a ‘teach back’ or ‘show me’ approach provides the opportunity for people to demonstrate they have understood (Parker, 2000; Parker *et al.*, 2003). Health professionals are advised to take the time to engage with people, listen and understand about the person’s social context and reconcile any information provided in that light (Kralik *et al.*, 2004b).

Some authors have provided instruments for assessing health literacy levels (Weiss *et al.*, 2005). The Rapid Estimate of Adult Literacy in Medicine (REALM) appears to be the most frequently used measure to assess literacy (Davis *et al.*, 1998). The REALM (attached) is a screening instrument that is used to assess an adult person’s ability to read common medical words and lay terms for body parts and illnesses. It is designed to assist health professionals to estimate a person’s literacy level so that the appropriate level of patient education materials or oral instructions may be used. The actual test appears very simple to follow and only takes two to three minutes to administer and score. Determining an individual’s health literacy status however, may not be helpful to people who may already be experiencing social disadvantage and stigmatisation. If not conducted discreetly, the person’s sense of self may be further diminished by a screening process which singles them out as having a low level of health literacy.

Nurses have been located as primary advocates, mediators and movers when working with people in healthcare settings who have low health literacy (Mayer *et al.*, 2004;

Cutilli, 2005), however all health professionals are charged with developing an awareness of people who may have poor health literacy and adjust practice and education to suit the individuals needs.

## **SELF EFFICACY**

Self efficacy is a widely accepted construct in social learning or social cognitive theory (Bandura, 1977; 1978; 1982; 1986). It is about perceptions of personal control and emphasises the role of vicarious learning in acquiring and modifying behaviour (Murphy *et al.*, 2003). The association between self efficacy and engagement in health behaviours is well established. Over the past two decades there have been numerous studies focusing on factors which support people to engage in the behaviour necessary to manage the chronic illness they live with (Holman *et al.*, 1992; Lorig *et al.*, 1999; Lorig *et al.*, 2001a; Katz *et al.*, 2002; Ewart, 1992; Toshima *et al.*, 1992; Carroll, 1995; Senécal *et al.*, 2000; Lev *et al.*, 1998; Smarr *et al.*, 1997; Lev *et al.*, 2001; Robinson-Smith *et al.*, 2003). The findings of these studies have shown a positive relationship between the enhancement of self efficacy and the uptake of self care behaviours. Some of these behavioural changes involve difficult lifestyle adaptations such as the uptake of physical activities for people experiencing painful joints (Holman *et al.*, 1992).

The stronger the person's belief in their efficacy, the higher the goals they set for themselves and the firmer their commitment to engage in the intended behaviour, even if failures have occurred (Schwarzer *et al.*, 1995). For example, there is evidence that high levels of self efficacy are statistically significant predictors of better arthritis management

outcomes such as ability to manage pain, conduct activities of daily living, control stress and fatigue, better psychological functioning and mobilising of social networks (Marks *et al.*, 2005; Smarr *et al.*, 1997). Within the Arthritis area, it is well recognised that fostering arthritis self management based on self efficacy leads to better functional status without exacerbating pain and more positive health outcomes (Penninx *et al.*, 1997; Schiaffino *et al.*, 1995; Kovar *et al.*, 1992; Alderson *et al.*, 1999; Hammond *et al.*, 1999; Hammond *et al.*, 2001). In addition, high self efficacy levels predict attendance and participation in health interventions and adherence to health recommendations (Taal *et al.*, 1993; Brus *et al.*, 1997; Grurcsik *et al.*, 2003). There have been similar positive results in other studies focussing on a range of other chronic diseases (Lorig *et al.*, 2001b; Lorig *et al.*, 1999).

### **What is self efficacy and how would high self efficacy be recognised?**

Self efficacy describes the interaction between behavioural, personal and environmental factors in health and disease. The theory of self efficacy proposes that the individual's personal confidence beliefs about the capacity to perform health behaviours influences which behaviours the person will engage in (Sarkar *et al.*, 2006). Self efficacy is an individual's estimate or personal judgment of his or her own ability to achieve a specific goal. (Schwarzer *et al.*, 1995) explain that before an action is taken, it is pre-shaped in thought and people anticipate either optimistic or pessimistic scenarios according to their level of self efficacy.

Albert Bandura is a leading authority on the construct of self-efficacy. According to his work, individuals with high self efficacy have high self esteem, are optimistic and have a strong sense of their own competence (Bandura, 1994). They are likely to have a personal sense of control and choose to undertake tasks that are challenging. They set themselves bigger goals and are committed to them. People who have high self efficacy often appear to put in more effort to achieve a goal and are more resilient once the action is taken. Should there be setbacks they recover more rapidly and continue pursuing their goal. They are typically confident and more comfortable with change and will approach new situations and environments with enthusiasm (Schwarzer *et al.*, 1995).

### **Strategies to enhance Self Efficacy**

The level of self efficacy a person has is able to be manipulated with the appropriate experiences and support, hence there is growing evidence of the benefit of incorporating self efficacy enhancing strategies into self management programs (Marks *et al.*, 2005; Kralik *et al.*, 2006). Individuals are enabled to undertake self care activities and to manage chronic illness in a manner which maintains their physical and psychological wellbeing. Marks *et al.*, (2005) make the important point that beneficial outcomes resulting from self efficacy enhancing strategies in the context of a self management program are without the risks and the cost of medications and surgery. Self efficacy enhancing self management education strategies include the following (Marks *et al.*, 2005):

- Use a variety of learning strategies including lectures, discussions, brainstorming, demonstrations, goal setting, contracting, modeling, mental practice, homework,

recall-enhancing methods, workbooks, texts, and videotapes, and provide mutual aid and support.

- Involve significant others, such as spouse or family members, and encourage collaboration with other health care providers and self-efficacy of caregivers.
- Foster self-management of exercise, food selection, weight control, fear, pain, depression and anxiety, and related self-monitoring strategies in small steps.
- Apply encouragement, persuasion, and direct or indirect support for the desired changes.
- Foster self-appraisal of emotional and physiological responses, decision making, and the necessary knowledge, skills, and problem-solving ability to deal with disease-related issues across different domains.
- Use trained educators, a detailed manual, and multi-component teaching strategies with content drawn from both patients and practitioners.
- Use both individual and small-group intervention approaches, especially collaborative and active participation strategies.

The relationship between high self efficacy and beneficial outcomes for people managing chronic illness is mapped out by Marks *et al.*, (2005). Implementing self efficacy enhancing interventions for people with chronic health conditions leads to improved affect, increased motivation, higher functioning, adherence to treatment and better social and clinical outcomes. The benefits are thought to be far reaching. With greater self efficacy for managing chronic conditions it is proposed that the use of healthcare services will decrease with resultant lower healthcare costs.

Marks *et al.*, (2005) make recommendations of approaches to increase self efficacy which are based on the work of Bandura, (1996) and Stretcher *et al.*, (1986). To enhance self efficacy for a given behaviour and build confidence in one's ability, the following strategies are suggested (Marks *et al.*, 2005):

- Identify and reinforce the patient's past and present successes or achievements.
- Direct the person to observe successful behaviours and coping mechanisms of similar others, even if this involves having them alter or expand their social network
- Provide positive feedback for the person's efforts or encourage people in their social network, such as family members or friends, to do this.
- Facilitate the person in adopting new health behaviours by ensuring that they do not interpret incorrectly how they are feeling. e.g., if a person felt anxious about undertaking a new behaviour, it would be important to normalise this reaction and reassure that it will diminish as the person becomes more familiar with the behaviour.

Having examined self efficacy, the focus now moves to the relationship between the healthcare provider and the person.

## **THE RELATIONSHIP WITH THE HEALTHCARE PROVIDER**

Traditional medicine has focused strongly on the person complying with the prescribed medical regime. Non compliance by people was considered to be problematic, but with the increasing number of people living with chronic illnesses this approach has been considered no longer realistic or effective. The ineffectiveness of the traditional model when applied to the chronic illness context with the clinician as expert is evident in the large body of literature on non-compliance. Rapley (1997) makes the point that compliance is unlikely or realistic when the treatments will be long term, consisting of complex prescribed regimens involving often difficult behaviour change and which interferes with a person's lifestyle habits and preferences. Indeed Rapley suggested that it is more helpful to view non compliance as the norm and rather than problematising it, conceptualising it as an adaptive behaviour from the person's perspective (Rapley, 1997). Models of care, where health workers tell people what to do and try to motivate them to change, are often ineffective (Thorne *et al.*, 2003). Precisely because people's day-to-day decisions have a tremendous impact on their health, they must be acknowledged by health professionals as active, informed participants in the health care process (Kralik *et al.*, 2004a).

Healthcare providers have an important supporting role for people learning to self care when living with long term illness. There is ample evidence in the literature that elements of the physician's relationship with the person such as communication, empathy and trust can influence the person's ability to self care (Vermeire *et al.*, 2001; Bonds *et al.*, 2004; Martini *et al.*, 2001; O'Brien *et al.*, 1992; Aikens *et al.*, 2005; Thorne *et al.*, 2004; Heisler

*et al.*, 2002). When qualitative research seeks the person's perspective, the findings repeatedly point to the supportive function of healthcare relationships as critical to the way a person adapts to and self manages disease (Charmaz, 1992; Thorne, 1993; Thorne *et al.*, 2003).

Reporting on the voices of research participants living with chronic disease, (Thorne *et al.*, 2003) conclude that professionals are seen as valuable to self care decision making when they demonstrate respect for the person's experiential expertise and judgement and where they have a real interest in promoting self care decision making. The professional perspective is seen to bring access to a different set of resources and benchmarks for interpreting aspects of illness progression. Health professionals could offer new information on developments in illness management, the meanings of new signs and symptoms and a different interpretation of illness cues (Thorne *et al.*, 2003). Their input could dovetail and complement the complex, mysterious, unpredictable process of learning to self manage illness.

Qualitative research conducted by Thorne *et al.*, (2001) found with people living with diabetes associated 'major turning points' in their self care journey with their experiences with professionals. The participants' responses reflected three domains of understanding about healthcare support, these being the stage within the process of learning expertise in which the support occurred; understanding the intended outcomes of self care decision making; and the socio-historical context in which the supportive interactions took place. To enhance our understanding of the issues associated with enacting and interpreting

support from healthcare professionals these domains are now considered.

- **The stage within the process of learning expertise in which the support occurred**

Participants recalled a developmental process of transforming toward a point of readiness to take responsibility in disease management. The nature of support from healthcare professionals needed to change over time as the person progressed through different stages. Participants did not suggest that health professionals only respond to their needs at the present time. This was sometimes experienced as obstructive. Rather participants found it useful for healthcare professionals to orient them to what lay ahead in terms of knowledge and skills. Clearly professionals need to be sensitive to the stage of development that the person is at but also pave the way for the transformation process. For example, in the early phase healthcare professionals need to familiarise the person with the types of skills and competencies that will be required in order to take on more responsibility.

- **Understandings about the intended outcomes of self care decision making**

A vital aspect of support in learning diabetes self care involves transcending a compliance model “and developing an intricate and sophisticated ability to make effective and astute modifications to the self care regime” (Thorne *et al.*, 2001:p.86). This is about considering medical information in light of bodily cues, recognition of patterns and experiential logic. Through ‘body listening’ the

person gets to know how their body responds in many different situations and how to recognise early signs of different responses. Against a history of experiences in living day to day with illness, patterns emerge and the person can draw on past experiences to inform the best way to manage every day situations. The support provided by healthcare professionals is best aimed at assisting the person to modify medical advice to fit with the person's priorities and lifestyle, while maintaining a degree of control over illness. Rather than compliance with a prescribed medical regimen as the benchmark of self care decision making success, healthcare professionals need to work flexibly with the person to work out a self care decision making pathway toward meaningful outcomes.

- **The socio-historical context in which supportive interactions take place**

Medical knowledge is limited in that it becomes defunct over time as new knowledge becomes available. For people who are trying to find a way through diabetes care while living well it is frustrating to be told that previous information around which one's life is shaped is now defunct. People learn to distrust medical science and to trust their own knowledge about their bodies and lives. These participants stressed that healthcare professionals who were too aligned with the current medical thinking could not be effectively supportive. Supportive healthcare professionals were those who maintained an open mind with regard to medical information and invested in the view of the person as the most accurate, reliable source of knowledge about their body and life. These professionals sought partnership at the outset and facilitated the expertise of the person over time.

These findings raise the question of what is and what is not supportive, and point to the dilemma that what is supportive may be completely unrelated to what the healthcare professional believes and intends to be friendly, kind and helpful interactions. The best intentions can be experienced as obstructive and unsupportive when they undermine the person's control in self care decision making (Thorne *et al.*, 2001). This is an issue that healthcare professionals must be aware of in every interaction with the person since professional dominance is likely to undermine the potential usefulness of the healthcare relationship for the person. The findings of a number of studies indicate that people lied to practitioners because they knew that they would disapprove of their changes to the prescribed regime. From the participant's perspective they acted on the basis of intricate knowledge and experience of living with the illness and the changes enabled them to maintain the quality of life they desired along with appropriate physiological outcomes (Paterson *et al.*, 2001).

Research participants described practitioners who fostered true partnership as 'not necessarily warm and fuzzy' but rather they welcomed, heard and respected the person's input (Paterson, 2001). Such partnerships however, were not often experienced by these people. Health professionals did not in practice demonstrate their intentions and their promises of partnership, and empowerment was lost to allegiances to the biomedical model and professional dominance (Paterson, 2001). They identified two ways in which professionals undermined empowerment, these being by discounting the experiential knowledge they had from living with diabetes over time and by not supporting informed

self care decision making with the necessary resources (Paterson, 2001; Paterson *et al.*, 2001; Thorne *et al.*, 2000).

Many health professionals may not 'walk their talk'. Despite expressed intentions to be empowering and involve people in decision making about their care, people living with chronic illness report that frequently this does not happen in practice. They are not listened to when they do give input about their experiences or their perspective is discounted (Paterson, 2001). Some authors have questioned the capacity of health professionals to foster empowerment and participatory decision making (Paterson, 2001). Even when practitioners promote participation in decision making, the outcome can be a devaluing of the person's capacity to actively participate (Paterson, 2001). Health professionals communicating expectations of compliance may effectively discount the experience of the person and promises of empowerment turn out to be hollow rhetoric. Paterson (2001:p.579) locates the reason for these inconsistencies as being "the practitioner's positioning as the expert or sole authority".

A survey conducted in the United Kingdom revealed that while the popular perception is that the role of health professionals is the most important factor in enabling them to self care, in reality they state that health professionals are only playing a minor role in encouraging self care. More than half who had seen a professional in the last six months stated that they had not been encouraged to undertake self care and one third said they had never been encouraged to do self care by professionals (Department of Health, 2005).

### **What is important in the self care partnership?**

The importance of a partnership relationship between the clinician and person living with chronic illness is increasingly recognised in the more recent chronic illness literature (Koch *et al.*, 2004; Weeks *et al.*, 2003; Paterson, 2001; Thorne *et al.*, 2001; Wagner *et al.*, 2001; Funnell *et al.*, 2004; Glasgow *et al.*, 2003). But what do we mean by a partnership relationship? Weeks *et al.*, (2003) describe it as a relationship in which each person brings their own equally valued unique perspective such as experience, wisdom and motivation to the illness situation. A level of trust and intensity typically builds which can have a powerful impact on the therapeutic experience for the person and their self care capacity. These authors when referring to nurses emphasise “a shift toward greater emphasis on promoting the autonomy and authority of the client at the earliest possible point in the disease process and to build on that autonomy and authority at every opportunity” (Weeks *et al.*, 2003:p.27).

Wagner *et al.*, (2001) advocates for a relationship that acknowledges and is informed by the central role that people have in their care. The partnership relationship does not include ensuring that people comply. Writing about self management support, Glasgow *et al.*, (2003:p.5) state that “clinicians are responsible to provide information, evidence based care and support but not to ensure that people carry out a prescribed set of activities”. These authors also emphasise a style which acknowledges the expertise of person and works with the person’s frame of reference.

Funnell *et al.*, (2004) strongly articulate the importance of the person's autonomy in self care of diabetes. They assert that the decisions people make in everyday self care of diabetes have greater impact on their outcomes than those made by health professionals. The person decides whether to implement or disregard recommendations in their everyday life and the consequences of such decisions are experienced by the person. Hence they take the responsibility and have the right to self manage in the manner which best suits the wider context of their lives. This consequently becomes a learning process (Kralik *et al.*, 2004a). Funnell *et al.*, (2004) describe the role of health professionals as supporting people to make informed decisions to reach their goals and to remove barriers through education, offering appropriate care options, information and support. Fundamentally they state that healthcare professionals need to give up feeling responsible for people and to become responsible to them. According to Funnell *et al.*, (2004) this is the pathway to true collaboration between equals in diabetes care .

Holman *et al.*, (2000) when emphasising recognition of the patient's expertise suggest that the person has access to particular knowledge about their body and is therefore able to predict trends in illness patterns that are pivotal to effective self management. Due to the intermittent nature of the contact that health professionals have with people living with chronic illness, they are unable to accurately ascertain trends therefore the information the person brings is critical to effective illness management.

Von Korff *et al.*, (1997:p.1097) coin the term for their preferred model of managing chronic illness as 'collaborative management'. This is defined as "care that strengthens

and supports self care in chronic illness while assuring that effective medical, preventative, and health maintenance interventions take place.” Von Korff *et al.*, (1997) make the point that self care and medical care are complementary and effective collaboration between the person with chronic illness and their family and health care providers is likely to maximise the potential outcomes. The essential elements of healthcare that can enhance collaborative management include (Von Korff *et al.*, 1997):

- **Collaborative definition of the problems**

Bringing the healthcare provider’s definition of the problems together with the person’s definition of the problem is likely to be beneficial for the person.

- **Targeting, Goal setting, and Planning**

Joint involvement in focusing on the problem to be addressed, setting realistic objectives and developing an action plan is optimal

- **Creating a Continuum of Self Management Training and Support Services**

The ability to self care is enhanced by education and skill development. This can be done at an individual or group level.

- **Active Sustained Follow up**

Providing follow up support is a critical factor in the success of the program. Contact with people at regular intervals enables checking of medical and functional status, identifying complications early, an opportunity to modify self care practices accordingly and reinforce the person’s efforts. This might happen via the telephone which has been shown to be effective, home visits, electronic mail or mailed correspondence.

The National Health System in the United Kingdom identify essential reforms to the professional role in supporting people with long term conditions to self care (Department of Health (UK), 2006). These include:

- changing the way consultations are conducted with a shift away from the focus on illness and treatment
- increasing their own understanding, skills and confidence as a result of working with people living with long term conditions over time. Not feeling threatened by a well informed person. Recognising that the person knows more than anyone else about living with the condition.
- Structuring the relationship as equal, a meeting between two experts sharing different knowledge
- Promoting the type of discussion within which beliefs can be challenged, changes can be contemplated and experiences shared.

Having outlined the important aspects of the healthcare relationship regarding the ability to self care, the review now shifts to briefly consider the importance of peer support and social networks

## **PEER SUPPORT AND SUPPORT NETWORKS**

Glasgow *et al.*, (1998) when making recommendations for diabetes education stressed the importance of ongoing support for self management behaviours. The findings of a review conducted by Gallant (2003) support the potentially important role that family and friends play in chronic illness self management. Social support has been identified as an

important factor in the ability to self manage a long term medical condition (Kralik *et al.*, 2003). Greater levels of social support, particularly disease or regimen specific support are related to better self management behaviours (Skinner *et al.*, 2001; Lorig *et al.*, 1999).

Thorne *et al.*, (2003) state that self help and support groups are important to people living with chronic illness particularly around the time of diagnosis. For people living with degenerative conditions involving increasing disability and impaired functioning, their peer support needs continued throughout the disease. This was largely related to the sharing of experiences of coping strategies, exchange of information about aspects of managing life, contact with others who understand the challenges and the emotional support provided to each through the difficult times. The feeling of being supported by others who experience a similar life is critical (Catalano *et al.*, 2003).

The value of peer to peer teaching has been repeatedly emphasised by Lorig *et al.*, (1999) as a crucial element of self management education. Lorig *et al.*, (1999) confirms that a peer leader who acts as a positive role model will increase the person's self efficacy to be a confident self manager. People learn vicariously from their peers in a subtle but powerful manner. Consequently, providing opportunities for them to interact with peers who have experience of self care can encourage self care abilities.

## **DISCUSSION**

Having considered the four major areas identified in the literature as impacting on the ability to self care, we now return to explore the questions.

### **1. What enables and/or constrains the integration of biomedical and social understandings of the body and disease in the decision making and self-care practices of people living with chronic conditions?**

The ultimate goal in health communications is to promote healthy self care behaviours and well being when people are learning to live with chronic conditions. Self care decision making is well recognised as a complex, multi-dimensional activity. One of the major ongoing challenges involves sorting out a way forward through a mass of medical information, instructions and expectations and balancing this with the need to experience an enjoyable lifestyle. So what helps and hinders this delicate, complex process? The constraints and enablers to the integration and transference of biomedical and social understandings relate to the four areas identified by the literature as key to self care. From examination of these areas several factors can be located as pivotal to enabling or constraining the integration of biomedical and social understandings. They include:

#### **Enablers**

- Adequate levels of health literacy
- Healthcare facilities which support health literacy with a 'shame free environment' and employment of strategies and resources to overcome poor literacy. This needs to include health intermediaries who create a respectful, comfortable environment in

which to work with people.

- Healthcare relationships which recognise and respect the expertise of the individual about their body and lives, who locate and facilitate control for self care decision making with the person and who seek to find places where healthcare expertise can support the person's self care understandings and practices.
- Opportunities to interact with people in similar situations, to share experiences and learn vicariously from them about managing chronic illness.
- Opportunities to develop one's confidence and self efficacy through education and the healthcare relationship. This involves a particular strengths focused approach which builds on the person's sense of mastery and control. Incorporating self efficacy enhancing strategies into the approach taken with people learning to self care is considered to be an essential element.
- Access to resources. A key role for health professionals is to provide access to resources which remove barriers to self care. Health professionals are considered to have access to particular resources that are not widely available. Comprehension of written resources however may not lead to sustained behaviour change. Evidence revealed that a combined approach of face to face communication with repetition of information over an extended period, and written or multimedia materials were considered most effective.

### **Constraints**

- Limited health literacy
- Financial and social disadvantage

- Healthcare facilities which are not sensitive to health literacy issues and do not provide a supportive environment for healthcare interactions
- Healthcare professionals who are not sensitive to literacy issues
- Health professionals who maintain a biomedical focus on compliance and do not recognise the individual's experiential expertise and autonomy in self care decision making
- Health professionals whose allegiance is to professional dominance and who do not question biomedical thinking.
- Healthcare professionals who do not prioritise the person's unique life story
- Lack of opportunities to interact with people in similar situations and to witness other people's approach to self care
- Poor confidence and a low level of self efficacy. Lack of opportunities to develop self efficacy.

## **2. What can trigger critical turning points for people living with chronic conditions to move towards positive pathways in self care decision-making?**

The strongest trigger for critical turning points identified by people living with chronic illness in the literature is the healthcare relationship. People living with chronic illness identify that major turning points in learning to self care are associated with interaction with health professionals (Paterson, 2001; Thorne *et al.*, 2003). The healthcare relationship has the potential to unleash the person's insight, sense of competence, and motivation and direct it toward self care goals. Health professionals who are respectful of the person's experiential expertise and who locate control for self care decision making

with the person at the outset create a solid foundation of trust upon which the person can rely and gain personal strength and focus. These professionals endeavour to build the person's autonomy and control over time as he or she moves through the developmental process of learning to self care. Implicit in this process is the gaining of personal power and a reclaiming of the self as a person who is competent and has control in their lives. Along with this comes a sense of order to life again (Kralik *et al.*, 2005). This enables people to reach critical turning points and to progress in their self care capacity. People want to make positive decisions and changes in managing their health. They are ready to resume an enhanced level of control.

### **3. How do health professionals recognise readiness to self-care in a person living with chronic condition(s)?**

Recognising readiness to self care will involve multiple factors. How is the person responding to the challenge of living with a chronic illness? What does their behaviour indicate in terms of motivation, sense of self and competence? What are they saying? How are they interacting with peers? What is their attitude to change and adopting new behaviours? The key factor associated with readiness to self care in the literature is self efficacy. The literature emphasises the individual's level of self efficacy as pivotal to readiness to self care. Increases in self efficacy coincide with a shift in self. A person who has a high level of self efficacy demonstrates confidence and a positive sense of self. They show a willingness to engage in new behaviours, to trial new experiences and extend aspects of their life. They are optimistic, are likely to be interacting positively with peers and with health care professionals. These people reflect an attitude which

indicates that they wish to exert control of their illness and life. They are likely to be ‘hungry’ for information and skills. There is a return of hopefulness about the ability to effect the course of illness. These characteristics are likely to stand out to the healthcare professional who has their ‘antennas’ out in relation to self care.

## **CONCLUSION**

Self care is complex multi-faceted activity. The manner in which people locate themselves in relation to self care is also complex and intricately enmeshed with their sense of self and their access to the types of support and experiences which facilitate self efficacy, personal autonomy and a sense of mastery. Self care as a developmental process is about reclaiming a sense of order and control in one’s life. It is about getting back in touch with the self and realising the self is competent and has potential to shape one’s life, despite illness. It is about the motivation to attend to managing illness as one would manage other aspects of life. It is about the desire to live life as optimally as possible. To achieve these optimal health outcomes, individual and families need the skills that will enable them to communicate with health professionals, understand the relevant health information, navigate the health system and then link this information into the context of their own lives through self care decision making and resultant actions.

Healthcare professionals have a responsibility to review their roles with people living with long term medical conditions and to be aware of the issues raised by this review. They need to transcend compliance models and focus on what is important to the person. They need to ensure that they are responsible to people rather than responsible for them.

This review calls for a re-conceptualisation of the concepts of empowerment and shared self care decision making, and indeed healthcare professional support. The recent chronic illness literature makes it clear that the person is the one responsible for management of illness according to their priorities for life; the healthcare professional's role is to support the person to do this. This may be confronting to notions of medical and professional dominance. Yet with the increasing incidence of long term medical conditions and the inadequacy of the acute healthcare system to ameliorate their suffering there is little option but to reorient the healthcare services to be aligned with the person's perspective about what it takes to live well.

This means no lesser role for healthcare professionals; in fact it means a more salient role. If people living with chronic illnesses can be assisted to maintain a measure of control while living a lifestyle they prefer then much has been achieved and healthcare has met its full potential in the context of chronic illness.

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