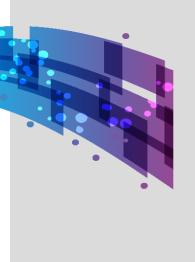# LITERATURE REVIEW

Self-Management Support and Health Literacy
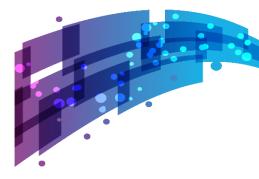
Table of Contents

Review of literature on self-management support and health literacy

<table>
<tr><td rowspan="4">The review of recent literature identified:</td><td>▸ what works in providing self-management support (SMS) in primary care settings</td></tr>
<tr><td>▸ the barriers to effective provision</td></tr>
<tr><td>▸ how health literacy affects health outcomes for long term conditions (LTCs)</td></tr>
<tr><td>▸ how low health literacy can be mediated with SMS.</td></tr>
</table>

Literature Themes

1. Primary care and self-management support

1.1 Managing change in primary care teams

Providing SMS in primary care requires more than a role change for a few staff, it needs to be a quality improvement strategy to change the behaviour and processes within health care organisations and between health services. This needs to be supported by change management.

In the Australian Primary Care Collaboratives, the psychology of change is used to identify individual and collective motivations for change in primary care teams. Clinical engagement with change as well as a team approach to change have been found essential to success. Data collection and evaluation is regularly carried out and interventions are altered where needed which encourages a series of small steps to change rather than one big leap. Practices are encouraged to seek expert guidance to help them identify what they want to accomplish, how they will know improvement has happened, and what needs to change to get improvement (Australian Primary Care Collaboratives 2016).

The attributes associated with high-performing primary health care are fundamental to the effective provision of SMS.

Bodenheimer et al (2014) identified the four foundation elements for high-performing primary health care organisations in the United States, as being: informed supportive leadership, data-driven improvement, providing team-based care, and linking patient outcomes to care teams. In New Zealand, this means primary care teams wanting to support self-management need to review the model of care they are providing to see how it can better meet the needs of people with LTCs. For example, this might include practice leaders trialling new approaches to care, introducing data management systems which easily collect and display care plan details for the care team and patient, meaningful coordination with other health and welfare services which effect patient well-being, helping to identify and address system and service barriers with patients, patients seeing the same care team on each visit, identifying meaningful outcomes of effective self-management (from the patient perspective), and connecting patient outcomes to care team performance.

1.2 Matching the SMS approach with the needs of patients

Accommodating the complexity of experiencing a long-term illness, or multiple illnesses and the resources a person needs to self-manage needs to shape the SMS model used in primary care (Sanders et al 2011). For example, it has been found helpful to prioritise the treatment of depression in people with multiple LTCs and engage patients with multiple LTCs in the co-design of interventions (Coventry et al 2014). Models of self-management designed around managing a single condition have often been ineffective, where the responsibility for change sits with patients and psychological interventions to increase self-efficacy are assumed to change patient behaviour.

Studies in the United Kingdom looking at the implementation of the SMS initiative, PRISMS, found that initial funding models in primary care did not support changes in the behaviour or processes of primary care teams, despite training being fully funded for primary care (Bickerdike and Wilson 2015; Taylor et al 2014; Kennedy et al 2013).

Kennedy et al (2013) attributed some of the failure to implement PRISMS in primary care being due to PRISMS not being perceived as substantially different to current practice. This similarity was reinforced by the use of already monitored biomed markers, such as glycemic control, as the measures of success for PRISMS.

1.3 Care planning

In NZ, care planning is an essential component of effective self-management as reflected by Care Plus funding for primary care assisting people with high health needs to manage LTCs (Ministry of Health website 2016).

Care planning is an opportunity to review, explore and establish what is important to a patient, is wanted in the future and how this can be achieved. If a patient is to both own and operationalise their plan, plans must be developed using patient-centred philosophy where patients are valued and enabled during the planning process (Raven 2014).

A review of research related to care-planning for people with LTCs highlighted that effective support needs to focus on the broad outcome of optimal life quality through having the knowledge, skills and confidence to manage their health effectively, rather than specific clinical decision-making or adherence outcomes (Carryer et al 2014). A recent review of Care Plus found health professionals still determining what is discussed during consultations and decision-making, with a strong focus on clinical matters.

Similarly, international research has found that while patients often want to take a more active role in decision-making and self-management, health professionals rarely endorse the behaviours needed to achieve this, e.g. patients offering their own ideas, doing independent research and information seeking or making independent judgements (Lhussier et al 2013).

Carryer et al (2014) found that Care Plus activities have focused on goal setting and motivational interviewing for lifestyle changes which are more relevant to the prevention of disease, than managing advanced disease. The authors also suggest that insufficient time, on the part of both patients and health professionals, has been a barrier to effective care planning. The authors also note that nurses in primary care question the utility and appropriateness of care plan production.

Newbold et al (2012) identified poor continuity of care as a barrier to care planning, which was often inconsistent and incomplete, done

through a number of different contacts, with action planning and goal setting rarely carried out. Lack of time in consultations was also perceived as a barrier to care planning by both professionals and patients. Allowing additional time for initial care planning consultations, encouraging health professionals to initiate care planning and self-management discussions, and reassuring patients that social and emotional issues need to be discussed were identified as being helpful.

1.4 Understanding patient perspective

Self-management requires patients to feel confident in managing their health, hopefully leading to health improvements. This is part of self-efficacy, a self-belief that one has the power, resources and skills to make positive changes and improve one's health. To self-manage people also need an understanding of their condition, the impact of their decisions and behaviours on their condition, and access to services and support when needed. Timely access to information such as test results is essential to support decision-making and self-management. Sampalli et al. note that self-management complexity is increased when managing more than one LTC (2016).

Peer support for diabetes self-management, especially when peers are identified by patients, such as friends and family rather than strangers, has been found to help with achieving positive health outcomes. This is described by Kousoulis (2014) as patient-centred self-management. Self-management and health literacy are forms of patient empowerment. However, a perceived transfer of responsibility for health management from health professional to patient is not always welcomed, particularly if self-management is conceptualised by a health professional as equating to compliance (Raven 2014; Ahmed et al 2014).

Self -management is demanding for patients and those living with more than one LTC or in social deprivation face significant barriers to self-managing. These barriers include capacity (access to time, resources, knowledge and energy), responsibility (the degree to which patients and health professionals agree about the division of labour in disease management) and motivation (willingness) to engage in self-management programmes (Coventry et al 2014).

Some patients do not engage with self-management because of insufficient personal resources, such as health literacy and resilience, or overwhelming personal circumstances (Kousoulis et al 2014). Patients living in social disadvantage are less likely to consider themselves as partners with health professionals or to participate in shared decision-making (Kennedy et al 2013). In addition, the self-management of diabetes is physically, intellectually, emotionally and socially demanding (Kousoulis et al 2014).

Coventry et al (2014) note that individuals and families have very different expectations about their health and what effective self-management means to them. People from socially deprived areas are socialised to see ill-health as an expected outcome in life and that self-management can do little to alleviate this situation other than manage treatment and pain. This effects goal setting and care planning decisions which are inherent in self management. Studies in the UK and US have shown socio-economically vulnerable patients have significantly different concepts of disease management and health expectations.

They are more likely to equate successful health management with keeping within self-imposed activity limits, getting adequate rest and managing pain.

This leads to a self-management focus on medication management and adherence (Coventry et al 2014). Patients with greater means are more likely to have life goals such as longevity, socialising and keeping up work and recreational activities.

Fransen et al (2012) similarly found that patients with low health literacy described self-managing as changing their behaviours as their condition worsened and required change, mainly equating behaviour changes with managing new and increased medications. There was an acceptance of the inevitability of worsening health and little understanding of prevention and the possibility of stopping disease progression or the wider consequences of disease progression on quality of life.

1.5 Features of effective SMS programmes

An analysis of ten studies of chronic diseases management identified the Stanford Chronic Disease Self-Management Program as the most common support programme provided. When compared to usual care, the Stanford programme led to modest short-term improvements in pain, depression, disability, fatigue health distress, self-rated health and quality of life but it is unclear whether these changes were clinically significant. The programme increased how often people exercised, engaged in stress and pain reduction activity and communicated with health care teams. The program was not shown to reduce primary care visits, emergency care visits, days in hospital or hospitalisations (Franek 2013).

Several studies into SMS have identified features which support effective programmes (Goodwin et al 2013; Taylor et al 2014) as well as SMS content areas or elements for patients (Bickerdike and Wilson 2015).

1.5.1 Structural features

Introducing self-management support within and across health care organisations has been identified as requiring: strong leadership to ensure that self management is prioritised; involving stakeholders in the process of change; training to ensure all staff have the necessary skills; resourcing to enable ongoing and sufficient delivery; and regular programme evaluation and improvement (Bickerdike and Wilson 2015). This paper also describes a whole-of-practice implementation being required in primary care to provide SMS.

Common structural features include:

▸ **Continuity of care**: being able to see the same lead health professional; and same support team is important as well as having trust in the people providing care. General practitioners and care teams need an identifiable patient group (panel) for whom they monitor needs and health outcomes.

▸ **Timely access to health care**: including planned regular contact and access to fast emergency care and problem-solving support; as well as knowing when, why and where to get appropriate support; and information being easily accessible.

▸ **Comprehensive support and care coordination**: relevant information about a patient is shared with all the care team and patient; patients are helped to prepare for each stage in their care and condition; patients are assisted to navigate the health and social support systems; support is individualised to a patient's needs; and general practitioners are able to help people manage the complexity of multiple LTCs.

▸ **Power balance:** patients are shown their knowledge and beliefs are important in the shared decision-making process and participate in the process and sense of self-efficacy is established where patients believe they are able to have a positive impact on their health (Bickerdike and Wilson 2015).

A change in organisational culture is often needed to integrate SM principles into routine care. Key elements include:

- strong clinical leadership
- involving stakeholders in change
- training staff to ensure staff have skills needed
- resources to enable delivery
- regular evaluation (Bickerdike and Wilson 2015).

1.5.2 Content of SMS programmes

The main elements of successful supported self-management include:

a) personalised care-planning
b) structured education and information, including peer support
c) access to health care professionals and trained specialist advice in regular structured reviews when needed
d) emotional, psychological and practical support, including from peers, family, friends and carers (Wagner, Austen and Van Korff 1996).

More recent research has looked at success factors and barriers within these elements.

a. Personalised care planning

Personalised care planning is a process where patients and health professionals identify and discuss problems related to LTCs and develop a plan to overcome these, including setting agreed goals and actions (Couleter et al 2015).

The resulting care plan is designed to help a person manage their own health and identify other support available. A review of randomised controlled trials in personalised care planning found 15 out of 19 studies (mostly about diabetes) had positive effects for at least one outcome measure.

Personalised care planning has led to small improvements in physical health such as lower blood glucose, lower blood pressure, reduced

cholesterol and reduced depression. Personalised care planning has also improved patient confidence and skills at self-managing and had a positive effect on self-care.

Personalised care planning interventions were delivered by a range of health professionals or coaches, including doctors, nurses and therapists as well as patients as peer coaches (Thom et al 2013; Van der Wulp et al 2012). Personalised care planning worked best when the process involved preparation (for patients and health professionals), record-sharing, care co-ordination, regular plan review, more intensive support from health professionals and becomes part of standard care (Couleter et al 2015).

b. Structured education and peer support

Education programmes which are sensitive to the health literacy needs of participants have been effective at increasing the diabetes knowledge and self-efficacy of all participants (Mackey et al 2016; Kim and Lee 2016). Self-management education can help build a sense of self-efficacy, people should participate in education when they are receptive to learning more about diabetes as this will maximise the impact of education. This is often not the case when a person is first diagnosed with diabetes (Chrvala, Sherr and Lipman 2015).

Diabetes self-management education is associated with significant improvements in glycemic control (Chrvala, Sherr and Lipman 2015). Diabetes education needs to build an understanding of the condition (diabetes knowledge) as well as self-care, health care and related services. Effective diabetes self-management education must be practical and feasible in a given setting.

The diabetes self-management programme developed in New Zealand by Titchener (2015) established roles and expectations, a common language, patient education, common ground, selected a management regimen, and empowers patients for long-term self-management.

c. Access, knowledge and power

Health professionals report the common barriers to shared decision-making as a lack of time, and a lack of agreement about the applicability of shared decision-making to the patients or the clinical situation. A 2014 review (Joseph-Williams, Elwyn and Edwards) identified barriers to shared decision-making from the patient perspective. The barriers were described in two ways. First barriers relating to the organisation of the health care system such as inadequate appointment times, no continuity of care, disruptive settings and poor workflow and communication between health professionals. Secondly barriers related to things which disrupt the decision-making interaction such as trust, communication skills, insufficient information and preparation support, the power imbalance, presumptions about the patient role and 'good' patient behaviours, as well as patients undervaluing their own expertise. This study identified that a patient having knowledge in a health situation does not equate to a patient having power in decision-making. Even when patients had information and were encouraged to participate in decision-making, a real or perceived power imbalance discouraged full participation in shared decision-making.

Patients need both knowledge and power to participate fully in shared decision-making. Decision-aids support patient participation during the decision-making process with health professionals, however they did not enable patients prepare adequately for the process which means they are unable to participate fully.

d. Emotional, psychological and practical support

Aikens et al (2014) had people with LTCs identify a peer support person to work with, someone they trusted and could rely upon. Peer support people received health status updates about patients via telemonitoring as well as advice for providing support. The positive outcomes from the initiative were enduring and significant, e.g. moving from non-adherence to adherence over six months. Patients and peer support people were very satisfied with the programme and outcomes. Peer support people described themselves as already trying to provide emotional and practical support to friends or family members and this programme gave them the skills and tools to do so more effectively.

e. Health navigators in primary care

In NZ, Doolan-Noble et al (2013) looked at the effect of a three-year pilot of health navigator services provided on the West Coast to people living with social complexity and LTCs as well as cancer. The navigators received training about LTCs and cancer, self-management in chronic care as well as the socioeconomic and cultural determinants of health. Primary care providers made referrals to the service and found the additional support valuable, particularly with problem-solving and accessing support for people. Those using the service were the most vulnerable in the community, mainly Māori living in the most deprived areas. The work of the health navigators reduced the inequities experienced by people, improving access to health care, including primary health care, community and social support. It was identified that people living with social disadvantage frequently require support above that generally available within the general practice setting. Caring for people living in social deprivation takes time with navigation assistance across the health and social sectors often necessary. Arranging transport to access services, contacting and coordinating health care and social services, as well as arranging financial support with Work and Income were typical navigator activities. Direct emailing to primary care was set up in response to concerns that navigators were not keeping primary care up to date with patient progress.

The study found that the navigators benefited from clinical education; understanding how to arrange access and overcome barriers for patients; and needed to be people who nurtured and maintained relationships with health and social service providers (Doolan-Noble et al 2013).

2. Managing Multiple LTCs

People experiencing multiple LTCs is becoming more common, however the health system is primarily designed to treat single diseases (Barnett et al 2012). Having more than one LTC, significantly increases the complexity of self-management. In a study of over 1.7 million patients in primary care in Scotland, Barnett found that most people with a LTC had multiple morbidities and more than half were under the age of 65. Young and middle-aged people with multiple LTCs were more common in adults living in social deprivation. Mental health disorders were also more prevalent in people with increasing numbers of physical health issues. There are more challenges for people living with multimorbidity and socioeconomic disadvantage. Continuity of care and care co-ordination are essential for people with multiple LTCs.

Person-centred care and long-term doctor-patient relationships were identified as helping patients and health professionals make decisions that need to balance clinical concerns with patient circumstances and preferences. A strong primary care system with the support of a multi-professional team is a key way of providing holistic, long-term care for people with multiple disorders, maximising quality of life and minimising disability and morbidity. This requires health services and systems to be designed specifically to support people with multiple LTCs (Barnett et al 2012).

Smith et al (2016) looked at 18 studies of multimorbidity mostly focused on changing the organisation of services in primary care and community care. Overall, the results of the studies showed limited clinical impact and demonstrate it is difficult to improve the health outcomes of people with multimorbidities.

Interventions involving new models of organisational support and targeting specific risk factors (such as depression and anxiety) or focused on addressing difficulties in daily functioning (such as fall prevention, physical activity levels, and smoking cessation) were somewhat successful.

Six of the 18 studies looked at patient interventions outside of health-care providers, such as patient education or self-management courses. These studies showed little change for patients with only two, focused on participation in activity and daily functioning (Garvey et al 2015, Gitlin et al 2009), showing some positive effect.

Sampalli et al (2016) identified the importance of using the patient perspective to set functional goals in managing multimorbidity. Patients were less motivated by the clinical results of single conditions than being able to carry out tasks and functions which gave them a better quality of life.

This study described the value of a well-coordinated multidisciplinary team supporting a wide range of healthcare needs including medical, dietary, psychological, psychosocial, functional, and rehabilitation needs. Coventry et al (2015) also refer to patients with multimorbidities not focusing on each condition but rather on managing multiple and interacting symptoms and treatments on a daily basis in order to meet the demands of everyday life. Understanding the experience of a patient managing this complexity is crucial to delivering interventions and supporting self-management (Coventry et al 2015).

3. Diabetes and Self-Management Support Interventions

A substantive evidence review of interventions in self-management carried out by National Voices (2014), found that:

▸ integrating self-management education and support into routine care with involvement from health professionals can improve patient knowledge, understanding, confidence and coping ability, as well as improve health behaviours

▸ lay-led generic self-management education courses can improve patient knowledge, understanding, confidence, coping ability and social support, but may have only a limited impact on clinical outcomes

▸ interactive online self-management programmes can improve patient knowledge, understanding, social support, health outcomes and health behaviours

▸ self-management programmes appear to be most effective when they are disease-specific (which is problematic for those with multimorbidity/multiple LTCs)

▸ tailored coaching that takes account of an individual's knowledge, skills and confidence can improve self-management behaviours and clinical outcomes

▸ proactive telephone support including health coaching, motivational interviewing and psychosocial support can improve confidence and self-management behaviours

▸ disease-specific group education, psychosocial interventions, tailored coaching for activation, self-monitoring and simplified dosing strategies have achieved reduced service use and costs as a result of appropriate use of medications, as well as fewer hospital admissions and unscheduled visits (National Voices 2014).

Self-management interventions in diabetes with a very specific focus on behaviour change or function have been effective at achieving change in the short-term, and sometimes in the longer term. For example, in NZ a twelve-week community programme focused on self-management education and group-based exercise for diabetes and pre-diabetes achieved demonstrable clinical benefit for participants (Higgs, Skinner and Hale 2016).

The programme was culturally acceptable to Māori and Pacific participants who also found it created a social support group of providers and participants that encouraged continued self-management. The programme was led by physiotherapists, with the support of physiotherapy students, a primary health care nurse, a pharmacist and podiatrist and involved two 90-minute sessions of education and exercise per week.

All of the health professionals received training in self-management education. Participants could invite family members or friends for support. Clinical results were measured at the start, end and three months after the end of the programme.

Thirty-six participants took part with a mean age of 62 years. Fitness levels, waist measurement and exercise time showed significant improvement over the programme and continued for a further three months. Self-efficacy improved but was not statistically significant. Participants identified the key success factors as forming therapeutic relationships with those providing the programme, more support, and a greater sense of self-management including motivation, confidence, safety and empowerment.

In California, a year-long online support programme was trialled for patients with uncontrolled Type 2 diabetes (Tang et al 2013).

The programme provided online glucometer readings and graphs, patient-specific diabetes status reports, nutrition and exercise logs, insulin records, messaging with a patient's health team, personalised nurse and dietitian advice and medicine management, and personalised texts and short education videos. The trial group showed a significant reduction in HbA1c after six months. While there was no difference at 12 months between the trial and control group HbA1c results, the trial group continued to experience improvements in HbA1c results. The researchers suggest this is because there was an overall improvement in diabetes care thanks to the trial programme increasing the profile of diabetes in primary care, and as a result both groups experienced improvements over the longer term.

Those patients who frequently used the online monitoring programme to regularly upload their glucose readings, achieved better results than those who were less engaged. The study showed that a nurse-led, multidisciplinary team can manage a population of people with diabetes using online management tools. However online support is mainly effective for patients who engage immediately and often with online tools and may be no more beneficial for other patients than standard primary care services supplemented with more discussion of diabetes control.

Establishing peer support and diabetes telemonitoring showed benefits in medicine adherence for people with poorly controlled Type 2 diabetes (Aikens et al 2014). Participants received weekly automated, interactive telemonitoring for three or six months. Participants could also choose a supportive relative or friend to get automated updates on the patients' health and guidance on how to provide positive reinforcement or facilitate change.

Those who involved a support person (42%) had significantly more improvement in short-term and long-term adherence than those without a support person. Peer support people were given video-

training before the programme started. Patients had to be comfortable with sharing their personal information with a peer, who was often an adult child of the patient. Patients with lower health literacy and lower income were more likely to choose to include a peer support person in their programme. Building on existing trusted relationships and increasing the knowledge of both the patient and peer support person was successful in improving adherence in within six months. By contrast, those who participated in telemonitoring but did not include a peer support person had a small short-term improvement in adherence at three months followed by an almost complete return to baseline adherence at six months.

A small pilot study in Auckland using text messaging program to provide self-management support to people with Type 1 or 2 diabetes sent regular reminders to people to check blood glucose as well as diabetes education and lifestyle advice (Dobson et al 2015). People could also reply with their blood glucose test results which produced a graphical display on a website they could access. Overall the three-month programme showed at least one positive impact for each participant including overall blood glucose control, improved exercise habits, diet and eating behaviour and mood.

Participants were satisfied with the content and usability of the messaging service and considered it culturally appropriate. The programme also offered an indigenous version which had a small uptake from Māori participants but gained positive responses. Participant evaluation suggested improvements that included adding a feature to enable two-way communication with a health professional, as well as making the text-reply function free, and greater flexibility in the timing and content. While most people could take part as they had a mobile phone, very few used the website tracking feature, reportedly due to a lack of internet access on personal mobile phones or at home.

4. Diabetes and Health Literacy

Adequate health literacy in relation to diabetes includes a range of skills that are critical to managing the condition and navigating the health care environment, such as health and disease knowledge, speaking and listening, reading, writing and numeracy. Health literacy skills specific to diabetes include reading labels on pill bottles, reading nutrient information on food labels, following written or oral directions, as well as understanding test results, health service and booking information, educational brochures, and informed consent documents (Bailey et al 2014).

A number of studies show health literacy is associated with mediating factors and behaviours which affect diabetes outcomes, such as self-efficacy, communication, self-care and adherence. However, the overall relationship between literacy and glycemic control and other diabetes outcomes is less clear (Bailey et al 2014; Al Sayah et al 2013). Studies suggest low health literacy is associated with an increased risk of diabetes complications, including hypoglycemia. Several interventions appear effective in improving diabetes-related outcomes regardless of literacy status, but it is unclear if these interventions fully overcome literacy-related differences in outcomes (Bailey et al 2014).

During in-depth interviews with primary care nurse and general practitioners, patients with low health literacy and diabetes were described as uninvolved, less motivated and not understanding self-management (Fransen et al 2012). Practitioners described themselves as repeatedly providing the same information to these patients and seeing no change in patient behaviour. Practitioners seemed to have little insight into the specific health literacy needs of these patients, how the repeated provision of the same information was unhelpful, or how they could better help these patients by discussing the challenges they face.

In another study of patients with Type 2 diabetes exploring the link between with low health literacy, self-efficacy and self-care, diabetes knowledge and self-efficacy were predictors of effective dietary self-care. However, self-efficacy was the sole predictor for foot self-care (McCleary-Jones 2011). Limited health literacy led to mistakes in judging blood sugar levels and the timing of medication.

Those with limited health literacy were the least confident in dealing with hypoglycemia or hyperglycemia, following a diet plan, and checking their blood sugar less often. Health literacy was significantly higher in those who were employed. Gender, marital status, living arrangements, years since diagnosis, receiving diabetes education, and education level, were not related to health literacy. Self-efficacy was significantly higher in employed participants and those receiving diabetes education. Diabetes self-care was significantly higher in the married participants, particularly married males.

McCleary-Jones (2011) notes that the relationship between health literacy, self-efficacy and self-care is not well understood. While patients with higher health literacy had higher self-efficacy, which in turn was highly correlated with self-care behaviours, there was no direct relationship between health literacy and self-care behaviours.

People with higher health literacy may feel more confident in their ability to carry out self-care actions or they may have a poor understanding of diabetes and low self-efficacy. Similar results were identified by Reisi et al (2016) and Bohanny et al (2013), where health literacy was independently associated with diabetes knowledge but not with medicine adherence resulting in glycemic control, yet diabetes knowledge was independently associated with adherence.

For patients with low health literacy, these studies suggest that both self-efficacy and self-care behaviours need to be supported, and that building health literacy alone does not guarantee improved self-care.

This also highlights the difference between health knowledge, which is often the focus of health literacy initiatives, and health skills, which are needed to carry out self-care behaviours. Health skills or actions can be performed without knowledge, and knowledge can be acquired without skill acquisition. Ideally skills and actions are practised and supported by an understanding of why actions are important and how behaviours affect health.

As such, interventions to increase self-efficacy need to take into account health literacy needs, and that people need both health knowledge and health skills relevant to diabetes. For example, if a patient has low health literacy they may need more time learning how to read and interpret glucose results and timing medication.

Low health literacy affects just under 60% of the New Zealand population (Ministry of Health 2010). Māori, Pacific, the elderly and those living in poverty are much more likely to have very low health literacy. In addition, those living in poverty find it harder to self-manage their LTC(s) as they have difficulty accessing resources and prioritising health when it is a struggle to meet the basic needs of life for themselves and their families (Kennedy et al 2013).

Studies suggest that limited health literacy is an indicator for oral communication problems, particularly when technical and medical terms are used in discussions between health professionals and patients. One study found patients with lower health literacy to be less likely to use online patient portals for communicating with health providers, even though people registered with the portal (Sarkar et al. 2010).

Other studies found no consistent association between health literacy and engagement with patient portals and health information technology (Glasgow et al. 2011, Mayberry et al. 2011).

Using a pre-post design, Kim et al (2016) examined whether health literacy status modified the impact of diabetes education classes on self-care and risk factor control. Participants with adequate and limited health literacy showed significant pre-post improvement in knowledge, self-care, and HbA1C. Improvements in HbA1c were similar for those with adequate and limited health literacy.

5. Health Literacy Assessment

Abrams et al (2014) describe health literacy is a dynamic systems issue reflecting the complexity of the health information being presented and care system being navigated. Addressing the challenge of low health literacy requires system-level changes for both health professionals and organizations. Organisational change is needed to stop what has been described as a wide gulf between what providers mean to convey verbally and in writing, and what patients and families understand and do. Implementing health literacy strategies at the system level can help transform the ineffectiveness of crisis care, shift the focus to patient-centred care, and ultimately improve health access, quality, and cost management.

Although adequate health literacy contributes to diabetes self-management, many practical and theoretical questions remain about whether to measure literacy as a part of routine care, how to best measure health literacy, which health outcomes are associated with health literacy, the mechanisms by which inadequate health literacy affects health outcomes, and how interventions designed to support patients with limited health literacy might enhance patient outcomes (Bailey et al 2014).

Sarkar and colleagues (2010) found that patients with low health literacy have an increased risk of hypoglycemia and suggest that providers should be aware of patients' health literacy levels when starting medications, particularly insulin, in case of adverse events, e.g. increased risk of hypoglycemia.

However, knowing about a patient's low level of health literacy may not enhance the patient - health professional relationship or improve the patient's health outcomes. A randomised controlled trial examined the impact of telling doctors if a patient with diabetes had low health literacy (based on screening).

Doctors were significantly more likely to use a variety of communication strategies with patients with low health literacy. However, these patients did not end up with better glycemic control than those in the control group. Doctors also felt less satisfied with consultations with these patients and, in over one third of consultations, did not think it was helpful to be told a patient had low health literacy (Seligman et al 2005).

Whether or not to screen for limited health literacy in patients with diabetes is a challenging question. On the basis of the trial conducted by Seligman et al (2005), it does not appear that screening and feedback alone improves outcomes.

Although some research suggests diabetes specific measures may be of greater value than general measures for this population, more robust studies are needed to fully assess the reliability and validity of assessment and screening measures. In addition, instruments need to be broadened to include a more comprehensive array of health literacy and numeracy skills, such as speaking and listening.

Most health literacy and numeracy assessment or screening measures assess a narrow range of the health literacy skills and knowledge, largely limited to reading literacy and some numeracy skills. Few measures consider other elements of literacy and numeracy such as information literacy, cultural literacy, and estimation and volume. Another limitation of assessment is the potential for stigmatisation which may result in patients disengaging from health services and health professionals (Batterham et al 2016).

An alternative which is increasing in use is the "universal precautions" approach to health literacy.

This requires health professionals to interact with every patient as if they might have health literacy needs, using questions and discussion to find out what patients do and don't understand about their health relevant to the clinical situation, and responding appropriately (Koh and Rudd 2015).

Universal precautions rely on health professionals having the skills and knowledge to identify and respond to patients' health literacy needs as part of good communication practice. In New Zealand, the universal precautions approach is the cornerstone of the Three Steps to better health literacy where health professionals use discussion to identify an individual's health literacy needs, draw on a range of appropriate communication strategies to build health literacy skills and knowledge, and then check the effectiveness of their communication by confirming patient understanding (Health Quality Safety Commission 2012).

Identifying each person's health literacy needs in relation to their LTC(s) and the demands of self-management should be part of every conversation supporting self-management. Providing effective SMS relies on relationship building, engagement and enablement.

When clinical and other staff identify health literacy needs, they need to be able to meet these needs.

This means using a range of appropriate communication strategies to build health literacy skills and knowledge and checking the effectiveness of the staff member's communication using techniques such as teach-back or questions, where the onus is on the health professional to take responsibility for the outcomes of communication, rather than to test patient comprehension (Health Quality Safety Commission 2012).

Conclusion

In New Zealand, the examples of supporting self-management which have been effective for patients and families, have required some fundamental changes to the model of care most common to primary care. Introducing SMS in primary care needs to involve a change management process to change both behaviour and processes in organisations and across services. It also requires people working in primary care to recognise the behaviour change needed (in themselves and their organisations) and receive training and support to make the necessary changes.

The attributes associated with high-performing primary health care are fundamental to the effective provision of SMS. These attributes include supportive leadership, using data to inform improvements, taking a team-based approach to care and teams being linked to patient outcomes. Continuity of care, timely access to care as well as adequate time for care planning are also components of successful SMS programmes.

Peer support programmes, where peers are identified by patients and receive ongoing training, also show positive outcomes for the self-management of some conditions, in particular diabetes. Interventions to improve self-efficacy which also build the relevant health knowledge and skills people need to understand both why and how to better manage their health, have also led to gains in effective self-management.

People being supported to self-manage are often living with multiple LTCs and require comprehensive support and coordination, which can be effectively provided by non-clinical roles such as health navigators (with access to and support from clinical staff when needed) as long as there in continuity in the care and support provided.

Where people with multiple LTCs are also living with socio-economic disadvantage, they face significant barriers to self-management. Once again, the degree to which self-management can be a focus (for a patient) needs to be realistic and agreed between patients and health professionals. In these situations, it is also important for potential health outcomes to be discussed to ensure patient expectations aren't lowered due to living circumstance and low self-efficacy.

If the benefits of self-management are to be realised, it is essential that the ownership of decisions in managing LTCs sits with patients and involves the people they choose to include in the process. Care planning, which is patient-centred and patient-directed, is more likely to achieve positive health outcomes than planning led by health professionals and focused on a clinical agenda. At the same time, patient ownership and direction requires health services to prepare patients and families for this role, as well as provide the resources to enable self-management and self-management support.

Literature List

Abrams MA, Kurtz-Rossi S, Riffenburgh A, et al. 2014. Building Health Literate Organizations: A Guidebook to Achieving Organizational Change. URL: www.HealthLiterateOrganization.org (accessed 1 May 2016).

Al Sayah F, Majumdar SR, Williams B, et al. 2013. Health Literacy and Health Outcomes in Diabetes: A Systematic Review. Journal of General Internal Medicine 28(3): 444–452. URL: http://doi.org/10.1007/s11606-012-2241-z (accessed 5 July 2016).

Aikens JE, Trivedi R, Aron DC, et al. 2015. Integrating Support Persons into Diabetes Telemonitoring to Improve Self-Management and Medication Adherence. Journal of General Internal Medicine 30(3): 319-326. DOI: 10.1007/s11606-014-3101-9 APCC (accessed 5 July 2016).

Australian Primary Care Collaboratives. 2016. Collaborative handbook: Closing the Gap
Australian Primary Care Collaboratives Program. Adelaide, South Australia.

Bailey SC, Brega AG, Crutchfield TM, et al. Update on Health Literacy and Diabetes. The Diabetes Educator 40(5): 581-604. DOI: 10.1177/0145721714540220 (accessed 12 July 2016).

Barnett K, Mercer S, Norbury M, et al. 2012. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. The Lancet 380(9836): 37-43. DOI: 10.1016/s0140-6736(12)60240-2.

Batterham RW, Hawkins M, Collins PA, et al. 2016. **Health literacy: applying current concepts to improve health services and reduce health inequalities. Public Health 132: 3-12. DOI: 10.1016/j.puhe.2016.01.001.**

Bickerdike L, Wilson PM. 2015. Supporting self-management: helping people manage long-term conditions. University of York. Centre for Reviews and Dissemination. URL: http://www.york.ac.uk/media/crd/Ev%20briefing_supporting%20self-management.pdf (accessed 1 June 2016).

Bodenheimer T, MacGregor C, Shafiri C. 2005. Helping Patients Manage Their Chronic Conditions. Oakland, California: California HealthCare Foundation. URL: http://www.chcf.org/~/media/MEDIA%20LIBRARY%20Files/PDF/PDF%20H/PDF%20HelpingPatientsManageTheirChronicConditions.pdf (accessed 10 May 2016).

Bodenheimer T, Ghorob A, Willard-Grace R, et al. 2014 The 10 building blocks of high-performing primary care. **The Annals of Family Medicine 12(2): 166-171. DOI: 10.1370/afm.1616.** (accessed 8 July 2016).

Bohanny W, Wu SF, Liu CY, et al. 2013. **Health literacy, self-efficacy, and self-care behaviors in patients with type 2 diabetes mellitus. Journal of the American Association of Nurse Practitioners 25(9): 495-502. DOI: 10.1111/1745-7599.12017** (accessed 1 June 2016).

Carryer J, Doolan-Noble F, Gauld R, et al. 2014. **New Zealand patients' perceptions of chronic care delivery. Journal of Integrated Care 22(2): 71-80. DOI: 10.1108/jica-12-2013-0048** (accessed 21 June 2016).

Chrvala CA, Sherr D, Lipman RD. (2016) Diabetes self-management education for adults with type 2 diabetes mellitus: A systematic review of the effect on glycemic control. Patient Education and Counseling 99(6): 926 – 943.

Coulter A, Entwistle VA, Eccles A, et al. 2015. Personalised care planning for adults with chronic or long-term health conditions (Review). **Cochrane Database of Systematic Reviews 2015**, Issue 3. DOI: 10.1002/14651858.cd010523.pub2.

Coventry PA, Fisher L, Kenning C, et al. 2014. Capacity, responsibility, and motivation: a critical qualitative evaluation of patient and practitioner views about barriers to self-management in people with multimorbidity. BMC Health Services Research 14(1). DOI: 10.1186/s12913-014-0536-y (accessed 1 May 2016).

Coventry P, Small N, Panagioti M, et al. 2015. Living with complexity; marshalling resources: a systematic review and qualitative meta-synthesis of lived experience of mental and physical multimorbidity. **BMC Family Practice 16(1). DOI: 10.1186/s12875-015-0345-3.**

Dobson R, Carter K, Cutfield R, et al. 2015. Diabetes Text-Message Self-Management Support Program (SMS4BG): A Pilot Study JMIR mHealth uHealth 3(1): e32 URL: http://mhealth.jmir.org/2015/1/e32/ (accessed 10 August 2016).

Doolan-Noble F, Smith D, Gauld R, et al. 2013. Evolution of a health navigator model of care within a primary care setting: a case study. Australian Health Review 37(4): 523-528. DOI: 10.1071/AH12038 (accessed 1 July 2016).

Foot C, Gilburt H, Dunn P, et al. 2014. People in control of their own health and care; the state of involvement. London: The King's Fund.

Franek J. 2013. Self-Management Support Interventions for Persons With Chronic Disease: An Evidence-Based Analysis. Ontario Health Technology Assessment Series 13(9), 1–60.

Fransen MP, von Wagner C, Essink-Bot ML. 2012. Diabetes self-management in patients with low health literacy: ordering findings from literature in a health literacy framework. Patient Education and Counselling 88(1): 44-53.

Garvey J, Connolly D, Boland F, et al. 2015. OPTIMAL, an occupational therapy led self-management support programme for people with multimorbidity in primary care: a randomized controlled trial. **BMC Family Practice 16(1). DOI: 10.1186/s12875-015-0267-0 (accessed 2 June 2016).**

Giltin LN, Hauck WW, Dennis MP, et al. 2009. Long-term effect on mortality of a home intervention that reduces functional difficulties in older adults: Results from a randomized trial. Journal of the American Geriatrics Society 57(3): 476–81.

Glasgow RE, Christiansen SM, Kurz D, et al. 2013. Engagement in a diabetes self-management Website: Usage patterns and Generalizability of program use. Journal of Medical Internet Research 13(1):e9. DOI: 10.2196/jmir.1391 **(accessed 2 June 2016)**.

Goodwin N, Sonola L, Thiel V, Kodner DL. 2013. Co-ordinated care for people with complex chronic conditions. Key lessons and markers for success. London: The King's Fund. Higgs. http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/

co-ordinated-care-for-people-with-complex-chronic-conditions-kingsfund-oct13.pdf (accessed September 25, 2016).

Health Quality Safety Commission. 2015. Three steps to better health literacy – a guide for health care professionals. Health Quality Safety Commission. New Zealand

Higgs C, Skinner M, Hale L. 2016. Outcomes of a community-based lifestyle programme for adults with diabetes or pre-diabetes. **Journal Primary Health Care** *8: 130–139. DOI: 10.1071/HC15038 (accessed 20 May 2016).*

Inoue M, Takahashi M, Kai I. 2013. Impact of communicative and critical health literacy on understanding of diabetes care and self-efficacy in diabetes management: A cross-sectional study of primary care in Japan. BMC Family Practice 14(1). DOI: 10.1186/1471-2296-14-40 (accessed 10 June 2016).

Joseph-Williams N, Edwards A, Elwyn G. 2014. Power imbalance prevents shared decision making BMJ, 348 **g3178. DOI: 10.1136/bmj.g3178 (accessed 30 May 2016).**

Kennedy A, Bower P, Reeves D et al. Implementation of self management support for long term conditions in routine primary care settings: cluster randomised controlled trial. BMJ 346(may13 3): f2882-f2882. DOI: 10.1136/bmj.f2882.

Kennedy A, Rogers A, Chew-Graham C et al. 2014. Implementation of a self-management support approach (WISE) across a health system: a process evaluation explaining what did and did not work for organisations, clinicians and patients. Implementation Science 9(1). DOI: 10.1186/s13012-014-0129-5 (accessed 1 July 2016).

Kim SU, Lee A. 2016. Health-Literacy-Sensitive Diabetes Self-Management Interventions: A Systematic Review and Meta-Analysis. Worldviews on Evidence-Based Nursing 13(4):324–333. DOI: 10.1111/wvn.12157 **(accessed 1 July 2016).**

Koh HK, Rudd RE. 2015. The arc of health literacy. JAMA **314(12):1225-1226**. *DOI: 10.1001/jama.2015.9978.*

Kousoulis AA, Patelarou E, Shea S, et al. 2014. Diabetes self-management arrangements in Europe: A realist review to facilitate a project implemented in six countries. BMC Health Services Research 14(1):453. DOI: 10.1186/1472-6963-14-453.

Lai AY, Ishikawa H, Kiuchi T, et al. 2013. Communicative and critical health literacy, and self-management behaviors in end-stage renal disease patients with diabetes on hemodialysis. Patient Education and Counseling 91(2):221–227. DOI: 10.1016/j.pec.2012.12.018.

Lhussier M, Eaton S, Forster N, et al. 2013. Care planning for long term conditions: a concept mapping. Health Expectations 18(5):605–624. DOI: 10.1111/hex.12063.

Mackey LM, Doody C, Werner EL, et al. 2016. Self-Management Skills in Chronic Disease Management: What Role Does Health Literacy Have? Medical Decision Making36(6):741–759. DOI: 10.1177/0272989x16638330 (accessed 1 June 2016).

Mayberry LS, Kripalani S, Rothman RL, et al. 2011. Bridging the digital divide in diabetes: family support and implications for health literacy. . Diabetes Technology & Therapeutics 13(10):1005–1012. DOI: 10.1089/dia.2011.0055.

McCleary-Jones, V. 2011. Health literacy and its association with diabetes knowledge, self-efficacy and disease self-management among African Americans with diabetes mellitus. **Association of Black Nursing Faculty Journal** *22(2):25-32.*

Ministry of Health. 2010. Kōrero Mārama: Health literacy and Māori. Wellington: Ministry of Health.

Ministry of Health. 2011. Whanau Ora: Transforming our futures. Wellington: Ministry of Health.

Ministry of Health. 2016. Self-management Support for People with Long-term Conditions (2nd edn). Wellington: Ministry of Health.

National Voices. Supporting self-management. 2014. http://www.nationalvoices.org.uk/publications/our-publications/supporting-self-management. Accessed September 25, 2016.

Newbould J, Burt J, Bower P, Blakeman T, Kennedy A, Rogers A, Roland M. Experiences of care planning in England; interviews with patients with long-term conditions. BMC Family Practice 13(1):71. DOI: 10.1186/1471-2296-13-71 (accessed 1 June 2016)

Raven M. (2015) Patient-centred care and self-management support in primary health care. PHCRIS Research Roundup Issue 41 March 2015 ISSN 1839-6348

Reisi M, Mostafavi F, Javadzade H, et al. 2016. Impact of health literacy, self-efficacy, and outcome expectations on adherence to self-care behaviors in Iranians with type 2 diabetes. Oman Medical Journal 31(1):52–59. DOI: 10.5001/omj.2016.10.

Sarkar U, Karter AJ, Liu JY, et al (2010). Hypoglycemia is More Common Among Type 2 Diabetes Patients with Limited Health Literacy: The Diabetes Study of Northern California (DISTANCE). Journal of General Internal Medicine 25(9):962-968. DOI: 10.1007/s11606-010-1389-7.

Sampalli T, Dickson R, Hayden J, Edwards L, Salunkhe A. 2016. Meeting the needs of a complex population: A functional health- and patient-centered approach to managing multimorbidity. Journal of Comorbidity 6(2):76–84. DOI: 10.15256/joc.2016.6.83.

Sanders C, Rogers A, Gardner C, Kennedy A. 2011. Managing "difficult emotions" and family life: Exploring insights and social support within online self-management training. Chronic Illness 7(2):134–146. DOI: 10.1177/1742395310390232.

Seligman H, Wang F, Palacios J, et al. 2005. Physician notification of their diabetes patients' limited health literacy: A randomized, controlled trial. Journal of General Internal Medicine 20(11):1077–1077. DOI: 10.1111/j.1525-1497.2005.00309.x.

Smith SM, Wallace E, O'Dowd T, et al. 2016. Interventions for improving outcomes in patients with multimorbidity in primary care and community settings. Cochrane Database of Systematic Reviews (3). DOI: 10.1002/14651858.CD006560.pub3.

Stellefson M, Dipnarine K, Stopka C. 2013. The chronic care model and diabetes management in US primary care settings: A systematic review. Preventing Chronic Disease 10. DOI: 10.5888/pcd10.120180.

Tang PC, Overhage JM, Chan AS, et al. 2013. Online disease management of diabetes: Engaging and motivating patients online with enhanced resources-diabetes (EMPOWER-D), a randomized controlled trial. Journal of the American Medical Informatics Association 20(3):526–534. DOI: 10.1136/amiajnl-2012-001263.

Taylor SJ, Pinnock H, Epiphaniou E, et al. 2014. A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS – practical systematic revIew of self-management support for long-term conditions. Health Services and Delivery Research 2(53):1–580. DOI: 10.3310/hsdr02530.

Thom, D.H., Ghorob, A., Hessler, D., et al. 2013. Impact of peer health coaching on glycemic control in low-income patients with diabetes: a randomized controlled trial. Annals of Family Medicine 11 (2):137-144. DOI: 10.1370/afm.1443.

Titchener J. 2014. A patient-centred clinical approach to diabetes care assists long-term reduction in HbA1c. Journal of primary health care 6(3):195-202.

van der Wulp I, de Leeuw JRJ, Gorter KJ, Rutten GEHM. 2012. Effectiveness of peer-led self-management coaching for patients recently diagnosed with type 2 diabetes mellitus in primary care: A randomized controlled trial. Diabetic Medicine 29(10):e390–e397. DOI: 10.1111/j.1464-5491.2012.03629.x.

Wagner EH, Austin BT, Von Korff M. 1996. Organizing care for patients with chronic illness. The Milbank Quarterly. 1996;74(4):511. DOI: 10.2307/3350391.