

# Self-management of patients with continuing care needs



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In essence, patient “ self-management” in relation to their health, encompasses a patient’s ability to handle an illness experience, to cope with undergoing treatment or make suitable lifestyle changes (Mulligan 2009). The concept was introduced to the health field by Kate Lorig who reached conclusions patients’ health and subsequently health service costs connected to them being an inpatient can be reduced by encouraging self-management (Lorig 2001).

These ideas are utilized in the generic long-term conditions model which emphasizes patients are not happy to be in hospital unless it is completely essential (DOH 2010), (Appendix 1). Effective self-management is also widely thought to reduce the likelihood of hospital admission, and many argue patients prefer to be given access to the information necessary to facilitate a respected voice in decision making processes (Gibson et al 2004, Newman et al 2004).

Linked to self-management is also the concept of self care - described as a requirement for success in controlling many chronic illnesses including diabetes (Berg 2007), and asthma (Cortes 2004). Self care is also described holistically as essential to the well-being of those with chronic illnesses with continuing care needs in nursing homes (Bickerstaff et al 2003), in the community, (Sharkey 2005), in hospital, intermediate, or rehabilitative settings (Singleton 2000, & Coleman 2004).

Conversely, low self-esteem, low health literacy, and/or deprivation are barriers to utilization of self-management strategies (Williams et al 2011). Those most likely to participate in self-management are young, middle-class

females (Coben 2005). Whilst those lacking literacy skills may not manage as well and family care-giving actions differ between ethnic and socio-economic groups (Larsen 2009). People who suffer a disproportionately high prevalence rate for chronic conditions are those with learning disabilities (Presho 2009) and ability to comprehend and enact management regimes might affect the efficacy of education initiatives with this population.

The Expert Patient Program, a 6 week, lay-led course teaching self-care, is a prominent initiative expected to be more cost effective than usual care (NSF 2010, Richardson 2007). Although the EPP's effectiveness to enable improvements in patient's self management ability regarding physical symptoms has been disputed (Gately 2007). Perhaps this is due to complex combinations of assorted medications, lifestyle adaptations, and bothersome side effects which are implicated as adversely affecting patient's perseverance with management plans (Barlow 2002, Touchette 2008).

GP business care plans developed in the UK propose introducing courses using self-management handbooks could reduce expenditure on asthma management (Appendix 4). Yet Cortes argues such asthma education programs neglect specific needs of older people identified as price of medication, problems undertaking management plans, poor quality of life, and troubles accessing health care (Cortes 2004). These opinions contradict the development of Lorig's ideas that self-management enables the best quality of life, but since healthcare information has the greatest effects on outcomes when it is goal orientated (Bodenheimer 2002, Barlow 2002, Kralik et al 2004), maybe older people's self management goals need more attention.

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Concurrent with increased longevity and lifestyle factors like poor diet, obesity and related chronic disease is predicted to increase greatly in prevalence (Wang 2010, Mulligan 2009, Armstrong 2005, and Keen 2010). Diabetes has well recognized links between weight and illness progression (Patel 2003), and has also recently been blamed for advancing cognitive deterioration through vascular dementia (Luchsinger 2001). Therefore tightening diabetes control in early stages may vastly improve future health as illness limits mobility, and dementia/retinopathy hamper potential to access self-care resources (Sinclair 2000).

Notably due to widespread sensitivity over weight, healthcare professionals should be non-judgmental towards patients with chronic conditions, especially considering psychological and psychosocial implications connected to adjustment to an illness, including guilt, fear, stigma, confidence loss, and isolation (Presho 2008).

It was observed during a TIDE (Type 1 Diabetes Education) diabetes specialist nurse led session that those with busy manual working lives find it difficult to take time to self-manage by adjusting insulin to activity levels or establishing a routine of carbohydrate counting and insulin adjustment. Others find calculations following the DAFNE (Dose Adjustment for Normal Eating) structure, hard to understand. Several patients who had suffered previous traumatic hypoglycemic episodes felt anxious about reducing insulin intake, and reported differences in advice from GP's, and nurses as well as confusion over new insulin analogues and devices. This indicates understanding patients as unique individuals, timing and convenience of interventions are important.

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Furthermore providing clear, consistent advice appeared allied to development of positive attitudes towards nurses' education interventions. Studies suggest structured education in type 1 diabetes has improved patients' maintenance of glucose targets and a reduction in occurrences of hypoglycemia changed people's attitudes to education (Heller 2009). Also those with greater understanding of and confidence in adjusting insulin appropriate to activity, with less anxiety over following a fixed regime to avoid hypoglycemia achieve top self-management in type 1 diabetes (Whitehead 2008).

On a stroke rehabilitation unit, patients with multiple conditions, particularly diabetes, asthma, and Parkinson's had restricted motor function. Yet nurses could provide encouragement for patients to express concerns, to relieve some psychological distress or help empower patients with the required self-confidence to make decisions (Costello 2009). Patients expressed difficulty with waiting for physios to engage in movement improving circulation, but self-administered some medication and carers views and choices underpinned care planning as recommended in Essence of Care benchmarks, via regular carers group meetings (DOH 2010).

Chronic disease is the leading cause of death worldwide (Larsen 2005) and literature establishes dependent people's needs are equality, rehabilitation, and independence. Furthermore security and dignity are important to older people's mental health (Presho 2008). On a local scale Manchester's operational plan illustrates emergency admissions for asthma is greatest in the North East and prevention is being addressed with annual health checks provision improving recently. Whilst the national continuing care framework <https://assignbuster.com/self-management-of-patients-with-continuing-care-needs/>

commenced in 2007 promises to ensure national equity of access to NHS funding for continuing care (NHS 2010).

Significantly “ Our Health and Wellbeing Today” (DOH 2010) suggests national morbidity is greatest from circulatory disease, which is particularly high in lower socioeconomic groups. These groups also have the greatest prevalence of anxiety and depression and have increased likelihood of having chronic conditions such as diabetes, which has led enquiring researchers to suggest depression as a factor that precipitates and perpetuates chronic conditions (Chapman 2005). Socioeconomics is also reported to determine medication adherence in asthmatics (Kaptain 2009). Victim blame might occur if expectations patients follow structured management programs ignore social contexts of illnesses, (Lindsay 2009) so emphasis should be on developing realistic goals.

The king’s fund review of self-management highlights that patients’ perceptions of self management differ according to how they receive a diagnosis, and these attitudes can change over time. Differentiation was noted between diagnosis of asthma or diabetes, where it was felt greater clarity existed, than of Parkinson’s disease for which diagnosis takes longer (Coben 2005). Disclosing a medical condition could also have implications for patients’ quality of life, and a study of anecdotes from Parkinson’s patients demonstrated those with confidence to disclose their illness subsequently achieved greater measured anxiety reduction (Presho 2008). Notably research shows patients fret significantly about psychological consequences of physical disability (Miller 2006).

Concealment could be due to perceived stigma and misconceptions about the disease or depression about associated decline, physical disability and being a burden (Moore & Knowles 2006). Alternatively challenges of symptom management such as sleeping problems and fatigue, sexual dysfunction and cognitive impairment might lead to depression (Schrag, Jahanshahi, & Quinn, 2001; Schreurs, De Ridder, & Bensing, 2000). Similarly emotional responses to asthma can impact upon attitudes towards taking prevention medication which enables control, and alongside non-adherence patient stress increases leading to depression, anxiety or inability to cope (Kaptain 2009).

Interventions aimed at managing pre-diabetes and mild asthma, that miss-managed, could contribute to the development of diabetes mellitus and chronic airway disease (Murphy 2007), are well developed and promoted by the charities Diabetes and Asthma UK (Appendix 3). It is especially important to promote good control since poor control negatively impacts on the affected person's quality of life and also their families (NICE 2008). Also individuals reportedly favor self-management because controlling their health affords greater sense of autonomy (Corben 2005).

The EPP has incentives of providing greater knowledge about treatment decisions with the underlying expectancy patients have authentic understanding of their own conditions, and greater recognition of patient's roles should give them self-confidence to protect future health (DOH 2001).

Illness progression might be reduced by lifestyle changes, therefore nurses have a role in promoting patients' independence, well-being, and in encouraging active ageing (NMC 2009).

In 2005 the Kings fund report highlighted that major challenges to promoting self management were; developing professionals' supportive skills, improving services and information available to facilitate patients' self-management, and becoming more flexible to fit compatibly around patients other commitments (Rosen 2005).

Dorothea Orem created a comprehensive model of nursing which can be applied to individuals to assess level of self-care ability (Appendix 2). Orem conceptualizes nursing as “ doing for” a disabled person with a self-care deficit, or assisting them/family to do for their selves (Orem 2003). Further to this Orem formulated three systems of nursing to apply, of which partially compensatory nursing seems appropriate for stroke patients, whilst a supportive-educative role suits structured education sessions (i. e. TIDE).

The effects of an education intervention delivering the DESMOND program (Appendix 5) for patients with type 2 diabetes to newly diagnosed patients over a period of 6 hours measuring cost effectiveness and quality adjusted years are reported by a randomized trial to have positive effects particularly on reducing patients weight and the amount they smoke (Gillett 2010).

Issues of self-efficacy and self-management prominent features of the DESMOND that have been found to build patients confidence (Davies 2008, Skinner 2006) are key to developing a sense of well being in rehabilitation (Presho 2008). Nevertheless, concerns nurses might have include doubts

about the patients being experts after what is actually a relatively short training period (Lindsay 2009).

Moreover, there could be internal conflicts for nurses between applying structural protocols (i. e.) or professional ethics, and accepting a patient's wish to continue a harmful behavior or health neglect. Farrell argued in 2004, active teaching on conditions and problem-solving to address medical issues better promotes self-efficacy than passivity (Farrell 2004). Yet it is important patients are equipped with enough knowledge to act as concordant partners and are supported with taking medications (Murphy 2007) (Appendix 7). Involving relatives in demonstrations of using metered dose inhalers is helpful with dependent asthmatic elders because direct patient observation by nurses supervising medication is often impossible once they have returned from hospital, (Schlenk 2004).

Ability to encourage self-management requires nurses to “listen”, and “respond” to the “concerns and preferences” of people in their care (NMC Code), as well as “sharing in a way people can understand, the information they want or need to know about their health” (NMC code). This may include providing written supplementation to verbal information such as education leaflets or management diaries, and allowing adequate time for adjustment and decision making. Patient's whose physical function has deteriorated significantly and continues to decline may be in a too highly dependent illness phase to benefit from strategies to return to normal function (Larsen 2009).

Cochrane authors conclude evidence showing contracts improve patient adherence to health-promotion in adult asthma studies is limited (Bosch-Capblanch et al 2007), which suggests patients' intentions when agreeing to follow advice is unreliable for predicting management outcomes. Patient self-reports are a simpler method of gleaning non-adherence information, are inexpensive, and possible in most settings (Schlenk 2004 cited by Ruppert 2008).

Research observes patients with Parkinson's disease using Alexander Technique had a reduction in depression and improved capacity to manage their disability (Clark 2003). "The essence of care is about getting to know and value people as individuals", (NMC Guidance for the care of Older People 2009) and nurses can recognize and respect peoples' role in their own care. Evidence also suggests motivational interviewing can reduce depressive attitudes towards illness situations and to encourage positive action to improve health outcomes, therefore perhaps GP's and practice nurses should increase these services (Home and Carr 2009).

Nurses can arrange social workers to speak to the patient, to engage with their family, find out their needs, compile appropriate packages of care and request doctors provide explanations of the mechanisms causing a stroke in dedicated wards which usually provide speech and language therapy, occupational, and physiotherapy. Dedicated stroke wards are shown by studies to improve outcomes after two years of patients who were independent prior to their stroke vis-à-vis ADL's without lengthening stay (Glader 2001 and Cochrane Stroke Unit Trialists' Collaboration 2007).

It can be a stressful time for patients and family having to make continuing care decisions; therefore patients might seek support from others who have been in their situation (Help the Aged 2009). Gathering information allows patients to manage their illness alongside doctors, and sharing plans with friends and family, explaining their importance, can help them to follow them, there are purportedly around 6 million carers in the UK combining caring with paid employment, saving £57 billion a year in care costs (Campling 2006, & Costello 2009).

Not every patient has supportive family members so professionals' and expert patients, and charities can be significant. Especially interventions tailored to marginalized patients needs such as X-PERT education for type 2 diabetics undertaken in Urdu (Diabetes UK 2009). In critical phases of illness, which may be the point where a patients continuing care needs begin, patients' relatives' main needs are for information, support and proximity (Henneman 2002). In the case of Parkinson's disease conveying to patients families the hope that there are strategies for managing the condition, particularly in early stages, might reduce fear, negative impact and sense of stigma (Moore & Knowles 2006).

Managing pain and discomfort is often considered a challenging aspect of caring, and psychological aspects also cause pain. Total illness effects make it important for patients to have supportive family members to listen to them to find out potential causes/remedies (Costello 2009). Practitioners should be sensitive to needs of carers as well as patients, and evidence suggests nurse-led stroke carer sessions, responding to individuals concerns would be helpful (Smith 2004).

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A study using the stress and coping model (Lazarus and Folkman) to identify a relationship between sleep deprivation and depression in family caregivers found that individuals self-reports underestimated their problems (Carter 2003). People may feel that because they know their relative they are capable of best comprehending and providing for them, and this could lead to guilt about accepting assistance with care (Nolan 2000). Research into respite care suggests family carers expressed needs for information, skills training or education and emotional support (Hanson 2001). To decrease feelings of powerlessness and support independence for those with chronic conditions Larsen proposes five interventions to recommend to carers (Appendix 6) (Larsen 2009).

Peak-flow monitoring, allergen avoidance, and the Buteyko method of symptoms control for mild asthma, based on correctly dosing steroids to maintain safe asthma control are found to be effective (McKeown 2003), as are diet, exercise, supplements and anti-diabetic medication as preventative strategies for type 2 diabetes, reducing heart attacks, microvascular disease, and death (Patel 2003). Though some studies suggest effectiveness reduces 1-3 months post intervention (Siminerio 2007).

Subsequently insight into self-management adherence remains complex and under-researched, but supports identifying barriers to adherence and taking action to remove these (Touchette 2008). In liberating the NHS the symbiosis of adult social care, carers, and the NHS is recognized and promises are made to improve the convenience of services to patients (DOH 2010).

To reiterate, according to the UK governments policy overall evidence suggests self-care results in beneficial outcomes and better service utilization, but this is largely based on primary studies as systematic reviews are reportedly too time consuming (DOH 2005-7). Systematic reviews also indicate clinical benefits for diabetic and hypertensive patients (Jordon and Osborne 2007). Although psychological benefits to patients appear widely well recognized (Lindsay 2009), patient self-determination requires more than medical management, (Greenhalgh 2009). Contrary to commissioners intentions studies show attendance at health services does not necessarily decrease following education sessions, although this may not indicate poor management as it could reflect success of techniques teaching patients confidence to converse with clinicians (Griffiths 2007).

Since GP's are also accused of stalling EPP progress, dubious about its efficacy and under referring patients (Jordon & Osborne 2007) it follows that nurses might take a key role in involving patients. The basis behind the EPP being best practice are aims to increase patient beliefs in health services efficacy, personal confidence, and ability to self manage (DOH 2010), therefore nurses are following policy implementing programs RCT's suggest achieve these outcomes (DOH 2005-7). Finally research highlights the importance of having clearer, comprehensive, shared definitions of self-management between health disciplines to reduce patient confusion and so professionals collaborate better (Godfrey 2011).

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