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## 5.4 Self-management

Nina Smolander, Annukka Isokoski,  
Marija Milavec Kapun and Tina Gogova

< One section of the DigiNurse Model is Health Literacy and Self-management, which is illustrated as one of the wheels in the DigiNurse Coach (Picture 1). Self-management refers to actions when people are actively participating and taking responsibility for their behaviour, well-being and decision-making (Culter & Collins, 2011). The term has been used since the 1960's, firstly in connection with rehabilitation related to chronically ill pediatric patients emphasising the patients' active role (Creer, Renne, & Christian, 1976). In terminology, self-management and self-care are often used interchangeably, and definitions have multiple dimensions (Jones, MacGillivray, Kroll, Zohoor, & Connaghan, 2011). However, a distinction is often made based on actions taken independently or in collaboration with healthcare professionals. The term 'self-management,' which is especially connected to chronically ill patients, is frequently used when functions are planned and performed in collaboration with healthcare providers. In contrast, the term 'self-care' refers to actions and decisions about health and well-being performed independently without the interaction of healthcare professionals. (Schulman-Green et al. 2012.) >

In the healthcare field, self-management is considered a comprehensive approach (Grady & Gough, 2014). It originates from patients' perceptions of their chronic conditions, the challenges experienced by them (Lorig & Holman, 2003) and patients' need analysis. It is a dynamic concept and includes various continuous processes in the medical, behavioural and emotional areas (Schulman-Green et al., 2012). In the DigiNurse Model, self-management is defined broadly as "individuals caring for themselves actively with the chronic disease(s)".

Self-management comprises several functions aiming to achieve the best possible situation in health and life for each individual patient. They consist of cognitive, behavioural and psychological requirements in cultural, social and organisational contexts. The healthcare professionals' core task in patients' self-management support is to act as a facilitator and support patients live as well as possible with their chronic condition, even when the patients' decisions don't level with the recommended advice (Morgan et al., 2017). In short, the self-management support is an ethical requirement for quality nursing (More information in Chapter 4.1); it is simply the correct thing to do for patients (Culter & Collins, 2011).

Through self-management support patients get encouraged with informed decision-making while deepening the understanding of symptoms and risk factors and their control (Mulligan et al., 2019). The healthcare professionals provide the support in the form of knowledge in illness needs and information of various interventions and activities of care (Schulman-Green et al., 2012). Also, it is fundamental that the nurse is aware of the potential barriers impeding the implementation of the care plan (Nagelkerk, Reick, & Meengs, 2006).

The cognitive self-management functions include the patients' ability to handle their condition and symptoms to perform health promoting activities and make informed decisions (Riegel, Jaarsma, & Strömberg, 2012). They need comprehensive information about their condition, care and expected lifestyle changes. They must have adequate skills to manage their treatment and medication and monitor themselves. (Jonkman et al., 2016; Mulligan et al., 2019; Riegel et al., 2012.) Educational process within self-management support is essential to develop and enhance these self-management skills. An individual's health literacy should be assessed to enable access, understanding and utilisation of health information (More information in Chapter 5.3). Equally, the healthcare services need to provide reliable and understandable information to patients with variable backgrounds and health literacy competences (Schulman-Green et al., 2012).

In addition to knowledge and skills, various other factors influence the self-management of a patient with a chronic condition: individual characteristics, motivation, health literacy (More information in Chapter 5.3) and resources, environmental and societal aspects, and the healthcare system.

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(Schulman-Green et al., 2016.) The motivation of self-management maintenance and treatment care must be intrinsic and supported by healthcare teams whenever necessary. People's habits, cultural beliefs, self-confidence on self-management added to competence, skills and widespread support form a fundamental basis for the self-management process. (Riegel et al., 2012.) The importance of the support from significant others, community and healthcare organisations has been emphasised strongly and adds valuable benefits to self-management (Grady & Gough, 2014).

Self-managing and living with a chronic condition comprise various lifestyle changes and coping with chronic illness in all aspects of life. In addition to healthcare and psychological resources, other personal resources may need to be activated, e.g. spiritual and community resources, to integrate the chronic condition into everyday life in an adaptive and meaningful way. (Schulman-Green et al., 2012.) It is the healthcare team's responsibility to encourage patients and their significant others to express their needs, feelings and perceptions and provide enough space and time for questions and information processing (Politi & Street, 2011). This will empower the patient and enable the implementation of a personalised care plan that increases the patient's commitment to self-management (Politi & Street, 2011; Barry & Engman-Levitan, 2012).

One of the fundamental processes in self-management is patients' ability to make decisions about their care and life while having a chronic condition. Both terms, shared decision-making and collaborative decision-making, have been used in the research literature, and the definitions are overlapping and vague at times. These concepts compliment rather than compete with each other. In both concepts the patient's role as an expert of their own condition (Jimison & Gordon, 2016) and in active participation in decision-making is recognised. Similarly, the communication between patient and healthcare professionals makes up a significant part of both definitions. The information of the patient's condition is provided and discussed openly together with the healthcare professionals and the patient. In collaborative decision-making, the emphasis is even more on the effort of working together with the patient to achieve a common, collaborated goal. (O'Grady & Jadad, 2010.) This requires enough cognitive and communicative capacities from both parties (Politi & Street, 2011).

Healthcare professionals need to have enough clinical expertise and abilities to deliver the information in an understandable, patient-centred and unbiased way. The most comprehensive clinical evidence should be discussed with patients honestly and understandably, including ex-

planations of all the treatment possibilities, even those with uncertain and insufficient clinical evidence and contradicting recommendations. This will provide ample information to patients and strengthen the trust between the healthcare team and the patient, even if the information is complex and difficult. On the other hand, the patients' capacities and state of mind might affect the receiving and processing of the information and acceptance of the presented options. (Politi & Street, 2011.) Patients might consider their decisions, be well-informed and have evidence-based knowledge or make the decisions emotionally or on autopilot without pondering the reasons or responses. Still, even well-informed and experienced patients may choose to go against the recommended health advice if the decision is based on contradicting values or reasons. The recommended advice may simply be out of the patients' reach. (Riegel et al., 2012.) The best possible equality of the encounter between healthcare professionals and patients generates mutual understanding and pertinent means for the patient's decision-making. The delivered information is incorporated into the patient's needs, values and preferences. (Culter & Collins, 2011.)

In collaborative management of a chronic condition, smooth interaction and information exchange between the patient and healthcare provider is important, and technology offers expanding opportunities to ease this (More information in Chapter 5.5) (Jiang & Cameron, 2020). Constant development of digitalisation brings new opportunities to support self-management through a variety of applications, platforms and technological interventions. They support the management of chronic conditions by integrating tele-monitoring to care. This makes self-monitoring and record-keeping easier, and following the trends in data and receiving instant feedback helps to adjust care and medication, accordingly increasing the autonomy of the patient in their own care. (Jiang & Cameron, 2020.) In addition, the information exchange improves as the real-time data sharing with care providers is possible (Hsu et al., 2016).

Technological interventions provide usable information on self-tracking several measurements and values not always directly in relation to the care of a chronic condition, e.g. sleep or stress. For example, the use of wearable self-tracking devices has spread health and well-being technology among the larger user groups. Even though health, well-being and fitness may not be the most important reasons to use these devices, ease of use, own personal interest and enjoyment are significant determinants. There is also a difference in user preferences based on gender. Female users are more health-tracking-oriented compared to males, whose interest in usage has

risen from technological specifications of wearable devices. Young people (<25 years) took wearables more seriously than the older generation, and support for well-being was a significant reason to start using them. (Pfeiffer, Entress-Fuersteneck, Urbach, & Buchwald, 2016.) Information regarding the user preferences might help with motivating patients to start using the wearable devices and other technical interventions.

The patients' experiences in using digital self-management interventions, such as tele-monitoring devices providing physiological data on blood sugar, blood pressure or activity, are promising. Patients feel well-cared for and assume a more active role during follow-ups and generally in their self-management. The usage of digital self-management interventions provides information for healthcare professionals that they can utilise for the patients' benefit. This helps in controlling medication management and above all improves patients' self-efficacy. In addition, the self-monitoring of physiological data supports the behavioural changes needed in the patient's life. (Morton et al., 2017.)

< The need and recommendations of self-management and self-management support have been researched and discussed in the literature for decades. Regardless of the consensus of its significance, there is a concern of the implementation in healthcare being questionable and insufficient, (Loriq & Holman, 2003; Morgan et al., 2017; While, 2019) and sporadically implemented (Culter & Collins, 2011). The reasons for hindering and withholding the implementation of structured usage of self-management support include several myths. Patients are believed to be uninterested in self-management or the self-management support is seen as a doctor's duty only. There are misconceptions of self-management being a simple task, easily taught and learned from materials or incompatible with clinical practice guidelines. (Légaré & Thompson-Leduc, 2014.) Some even think self-management support doesn't make any difference to the patients' lives (While, 2019) and doesn't involve patients' emotional support. Other common excuses for not integrating self-management support to daily nursing are the lack of time or misconceptions of performing effective support automatically. In addition, there are doubts whether self-management support has any real cost-effectiveness compared to the time invested in it. (Légaré & Thompson-Leduc, 2014.) >

There is no evidence supporting these myths or excuses (Légaré & Thompson-Leduc, 2014). Patients do have an interest in their self-management, and their knowledge and skills improve if interventions e.g. last long enough (4-8 weeks) and are delivered by professionals and even with the

help of peers (Mulligan et al., 2019). Through different self-management support interventions, motivation to care, trust in own skills and knowledge on diet, symptom control and lifestyle were found to be enhanced among chronic kidney patients (Donald et al., 2018). Equally, the control of asthma and lung functions resulted in improvement as patients participated in the Internet-based self-management programme (van der Meer et al., 2009).

Consequently, the self-management interventions do have cost-effective results, but these results must be assessed carefully. The self-management interventions vary, and comparing the effectiveness may be difficult. (van Eeden et al., 2016.) For example, nurse-led intervention enhanced breast cancer patients informed shared decisions and willingness to participate in decision-making. This resulted in opting for less invasive and less expensive procedures. (Berger-Höger, Liethmann, Mühlhauser, Haastert, & Steckelberg, 2019.) The lower procedure rates may decrease the financial income in hospitals, which creates an ethical dilemma if self-management support is thus neglected (Culter & Collins, 2011).

Well-performed self-management of chronic conditions brings benefits to both patients and healthcare providers. The healthcare system benefits from reduced costs due to decreased visits and admissions, and decreased complications. (Culter & Collins, 2011.) More importantly, patients gain higher self-confidence and control over their lives and well-being (Jimison and Gordon, 2016). Strengthening the patient's self-efficacy, autonomy and ownership of managing their chronic condition is important (Mulligan et al., 2019) and has a positive impact on the patient's health outcomes and quality of life (Jimison and Gordon, 2016).

Self-management, and its support with applicable self-management interventions, is a long-term and persistent process, but it should not be rigid. Healthcare professionals must maintain the contact with their patients, the patients' support network and the surrounding team of care providers, and tailor the support by recognising patients' fluctuating needs. The capability to react and be proactive in a flexible manner creates a wide spectrum of self-management support and utilises the resources effectively for the patient's benefit (Rotheram-Borus, Ingram, Swendeman, & Lee, 2012; Schulman-Green et al., 2012.) as well as helps patients navigate in applying the Chronic Care Model to reality (More information in Chapter 4.3). Therefore, healthcare professionals and organisations should engage themselves strongly to self-management support programmes and education (While, 2019).



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< In the DigiNurse Model (More information in Chapter 5.2), we suggest the use of the Chronic Care Model to provide a framework for professionals' self-management support and coaching as an approach to collaborative decision-making with coaching models as practical tools for it (More information about the Chronic Care Model in Chapter 4.3. and about coaching in 5.6 and 5.7). >

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