General Discussion

GENERAL DISCUSSION

The central aim of this thesis was to explore how nurses could effectively support patients with a chronic condition in dealing with the disorder in daily life. This was elaborated in three parts: I) patients' and nurses' experiences with and needs for self-management support; II) development of a self-management support intervention; and III) evaluation of self-management support interventions. In this final chapter, I will reflect on the main findings and provide implications for clinical practice and future directions for research.

I) EXPERIENCES WITH AND NEEDS FOR SELF-MANAGEMENT SUPPORT

We established that nurses mostly restricted their self-management support efforts to enabling patients to deal with the medical challenges of the condition. Nurses' views and patients' experiences were confirmed by another study of the NURSE-CC research group, in which nurse practitioners were observed during outpatient consultations (Ter Maten-Speksnijder, Dwarswaard, Meurs, & van Staa, 2016). The three distinct perceptions of nurses about self-management, patient's role and their own support role (Chapter 2) were largely congruent with a Q-study of the NURSE-CC research program, which dealt with nurses' perspectives on the goals of self-management support. Table 1 shows the similarities and differences about nurses' views on self-management between both studies (van Hooft, Dwarswaard, Jedeloo, Bal, & van Staa, 2015). One of the differences is that, in our study, outpatient nurses seemed unconcerned about reducing healthcare costs, whereas this was the main goal in the '*gatekeeper*' perspective described by van Hooft and colleagues. This is remarkable, since there is an increasing pressure of the Dutch government and insurance companies on healthcare professionals to provide affordable care of high quality (Katon et al., 2010; Schneider, O'Donnell, & Dean, 2009). Differences could be explained by variation in the target group and study design. In contrast to our study, where only outpatient nurses and nurse practitioners (NPs) from one university hospital were interviewed (Chapter 2), van Hooft and colleagues (2015) included nurses with various educational levels working in a variety of healthcare settings (e.g. mental healthcare, home-care and general practice). Also, van Hooft and colleagues (2015) used Q-methodology, a method specifically aimed at enlarging differences in views by searching for contrasts between values and believes (Stephenson, 1935; Watts & Stenner, 2012).

The definition of high quality of care will differ between patients (Hawkins, Kreuter, Resnicow, Fishbein, & Dijkstra, 2008). Our studies about patients' needs (Chapters 3 & 4) confirmed that people with chronic conditions have various tasks in managing the medical, emotional and social consequences of the condition (Corbin & Strauss, 1988; Lorig & Holman, 2003). At the start of the NURSE-CC research program, we were quite ignorant about what kind of self-management support patients wished to receive – and

Table 1. Similarities and differences between two NURSE-CC studies about nurses' views on self-management support

Been-Dahmen et al. 2015 (Chapter 2)	Van Hooft et al. 2015
'Adhering to medical regimen' - Self-management is the ability of patients to live as healthy as possible - Patients should adhere to prescribed medical regimens - To achieve behavioural change, nurses should provide information about the medical regimens.	*'Clinician'* - The main goal of nurses' support is supporting patients to be able to be treatment adherent. - Nurses holding this view combine education with proposing solutions for problems patients encounter.
'Monitoring symptoms' - Self-management is specified as patients' monitoring of medical symptoms and their ability to take action if things are not going well - Patients should take an active role to be better able to manage their condition - Nurses should provide education to equip patients for monitoring	*'Educator'* - The main goal of nurses' support is to instruct their patients so they will be able to manage their condition - Nurses holding this view found it important that patients are capable to deal with the symptoms and complications of their condition.
'Integrating illness in daily life' - Self-management is the patient's ability to cope with the chronic condition in daily life - Patients are the prime agents in determining how life can be adjusted to a chronic condition - Nurse should provide holistic support and help patients to adapt to their chronic condition	*'Coach'* - The main goal of nurses' support is supporting patients to integrate their chronic condition in daily life - Nurses holding this view have a holistic view on self-management support.
	'Gatekeeper' - The main goal of nurses' self-management support is reducing healthcare costs. - Nurses holding this view stimulated their patients to become less independent of health care professionals

from whom. From the patient's point of view, good self-management support does not only address the medical challenges, but also the emotional and social consequences of having a chronic condition (Chapters 3 & 4). These results were unravelled using the model developed in a qualitative review performed in the NURSE-CC research program, which indicated that patients need to receive *instrumental* (practical support e.g. to deal with medical issues), *psychosocial and relational support* from healthcare professionals, relatives and fellow patients (Dwarswaard, Bakker, van Staa, & Boeije, 2016). We found considerable similarities between the support needs of patients with a rheumatic disorder and those of recipients after kidney transplantation (Chapters 3 & 4). *Instrumental support* should include tailored provision of disease-specific knowledge and instruction. *Psychosocial support* should address the ability to share emotional issues with a nurse. *Relational support* should include the ability to discuss the social consequences of having a chronic condition. Another NURSE-CC study, dealing with the support needs of patients with head and neck cancer regarding the consequences of the disease and its treatment,

confirmed these needs (Peeters et al., 2018). Besides generic support needs, also differences between both patient groups were found, confirming that patients have generic and disease-specific support needs (van Houtum, Rijken, Heijmans, & Groenewegen, 2015). For example, patients with a rheumatic disorder wished to learn how to deal with symptoms and fluctuations, needed practical advice for self-managing, and appreciated being helped building self-confidence and empowerment by encouragement and reassurance (Chapter 3). Kidney transplant recipients wanted to be encouraged by positive feedback, receive training to develop self-awareness skills to recognise body signals, and receive support to find new daily life routines (Chapter 4). In contrast to patients with a rheumatic disorder, kidney transplant recipients indicated a more explicit need for sharing experiences with fellow patients. People with rheumatic disorders were of the opinion they had to 'do it themselves'; they saw self-management primarily as a patient's responsibility. Additionally, individuals with head and neck cancer fervently wished to receive support in dealing with the physical problems they experienced after treatment. Besides, they wished to receive support to build self-confidence to move on with their lives (Peeters et al., 2018). Although this could not be confirmed, these differences in self-management support may be related to differences in the nature of these chronic conditions. At least, it can be concluded that the need for holistic support is a common denominator for patients with a chronic condition and that all patients wish for an approach tailored to their condition and experienced challenges.

The results also demonstrated the existence of a significant gap between patients' need to receive holistic support and current nursing practice. Despite the claim of the nursing profession that nurses are experts in care-giving and apply a biopsychosocial perspective (Allen, 2015), providing self-management support from a broad perspective is not self-evident and the biomedical model of healthcare provision still appears to dominate. Above mentioned findings indicate that nurses, and other healthcare professionals, need to comprehend the importance of providing support in a broad perspective. Only when there is understanding changes in work practices can be achieved (World Health Organization, 2005). To achieve such understanding, health professionals should be made aware of the necessity of providing support from the biopsychosocial model of care to outpatients with a chronic condition.

Conclusion 1: Nurses tend to restrict self-management support to the medical challenges of patients with a chronic condition. In contrast, patients wish to receive self-management support that fits their medical, social and emotional needs and contributes to a successful management of everyday challenges.

We found that patients wished that nurses would inform about their individual support needs (Chapters 3 & 4). While the need to receive holistic support is generic, individual support needs still vary. For example, one patient may find it hard to deal with the misunderstanding of relatives, while another patient is struggling to find a balance between work-related activities and rest. A few patients did not want to discuss personal issues with their nurse and only wished to receive medical support. This emphasises again the importance of providing self-management support tailored to patients' individual support needs, which other researchers, too, have pointed out (Bos-Touwen, 2016; Trappenburg et al., 2013). Our research showed that nurses rarely provided tailored support and mostly used a type of traditional (standardised) patient education to promote their patients' self-management (Chapter 2).

Since there is no '*one size fits all approach*', assessing individual needs seems to be the first step in providing effective self-management support. By becoming aware of patients' individual support needs, preferences, values, requirements, and individual characteristics (National Clinical Guideline Centre (UK), 2012), nurses will be able to effectively tailor information, instructions and recommendations. Assessing individual needs is the first of the five phases of the self-management support process and is considered one of the necessary competencies for nurses to provide sufficient self-management support (Duprez et al., 2016; Glasgow, Davis, Funnell, & Beck, 2003; van Hooft, 2017). In addition, nurses must also acquire other competencies in line with the phases of the Five A's model (Glasgow et al., 2003; van Hooft, 2017). After Assesing patients' needs, nurses should tailor their information, instruction and advice to patient's individual needs (Advice phase). Collaborative goal setting (Agree phase) and helping patients to adapt with daily life challenges (Assist phase) are important. If needed, nurses should refer their patients to other healthcare professionals (Arrange phase). Overall, nurses should be able to form partnership with their patients. This also coincides with the current trend in healthcare to deliver person-centred care (Kitson, Marshall, Bassett, & Zeitz, 2013). To conclude, in person-centred care it is the patient who sets the agenda, not the nurse. We therefore need nurses who know how to coach and support their patients to their liking.

Conclusion 2: Tailoring information, instruction and advice is essential in providing adequate self-management support. Therefore, the first step of each self-management support intervention should be assessing patient's individual support needs, which should be repeated regularly as these may change over time.

II) DEVELOPMENT OF A SELF-MANAGEMENT SUPPORT INTERVENTION

In the past decade, the effectiveness of self-management support interventions has been much studied. Most interventions focused on the medical management of a chronic condition. Although many reviews conclude that these interventions are useful in practice, it was not clear what particular components of the intervention contribute to success (Jones, Lekhak, & Kaewluang, 2014; Radhakrishnan, 2012; Wenjing, Guihua, & Shizheng, 2015): for whom do these interventions work and in what circumstances? Many studies examined only one type of intervention (e.g. education), targeted at one specific chronic condition (e.g. diabetes type 2), and not specific developed for the use by nurses (Bentsen, Langeland, & Holm, 2012; Bonner et al., 2014; Kuo, Lin, & Tsai, 2014; Radhakrishnan, 2012; Song, Yong, & Hur, 2014). We added to the knowledge by providing more insight into the working mechanisms of nurse-led self-management support interventions with our Realist Review (Chapter 5). Successful interventions focus on patient's intrinsic processes such as motivation and self-efficacy; making that patients perceive an internal locus of control. While previous reviews have shown that solely providing education is ineffective (Barlow, Cooke, Mulligan, Beck, & Newman, 2010; Coster & Norman, 2009), nurses mostly use standardised patient education to improve their patients' self-management skills instead of applying interventions that activate patients (Chapter 2). To change patients' self-management behaviour, nurses should provide tailored information, reinforce their patients and combine patient education with skills enhancement. Involving relatives could enhance the effectiveness of self-management support interventions, too, as also was concluded in a qualitative synthesis about patients' needs in self-management support (Dwarswaard et al., 2016). Another working mechanism that our Realist Review revealed is that homogeneity in the target group of the intervention (condition, extent of motivation, recently diagnosed or not) had a positive effect on recognition and confidence. The above insights indicate that it would be worthwhile to develop holistic self-management support interventions that focus on improving the patient's intrinsic processes. We expect that recognition of these mechanisms will lead to successful self-management support. For this reason, a nurse-led self-management support intervention was developed within the NURSE-CC research program using the Intervention Mapping approach. The assessment of patients' needs was central to this intervention. Given that professionals exert a great influence on the outcomes of interventions (Clark, 2013; Disler, Gallagher, & Davidson, 2012; Macdonald, Rogers, Blakeman, & Bower, 2008), NPs received a two half-days training session before implementation. They learned how to carry out the intervention protocol and through role plays were trained in conversation techniques based on the method of Solution Focused Brief Therapy and Motivational interviewing. During the intervention period, NPs received booster sessions to discuss problems they encountered and practice conversation techniques. Feedback was provided through video recordings. This generic inter-

vention was tailored to the specific needs of individuals with head and neck cancer and kidney transplant recipients. The intervention for kidney transplant recipients was called the ZENN intervention, an acronym derived from the Dutch name (*ZElfmanagement Na Niertransplantatie*), which translates into Self-Management After Kidney Transplantation

The developed self-management support intervention is unique and new because it consists of several elements that, in combination, should lead to success: elements tested before, such as goal setting and motivational interviewing (Maes & Karoly, 2005; Miller & Rollnick, 2013; Ratner, George, & Iveson, 2012)

Conclusion 3: Since providing education alone is not enough to change a patient's behavior, effective self-management support consists of a combination of elements that intends to influence patient's intrinsic processes, such as motivation and self-efficacy.

III) EVALUATION OF A SELF-MANGEMENT SUPPORT INTERVENTION

Evaluating self-management support interventions is a complex affair, as reported before by others (Trappenburg et al., 2013), and it remains difficult to find hard evidence about the effectiveness. In our study, we also found no significant differences in patients' self-management behaviour, self-efficacy, quality of life and social support after completing the intervention (Chapters 7 & 8). This might potentially be ascribed to: the nature of the study design, the intervention itself was not so powerful, the small number of participants and some ceiling effects in the outcome measures (e.g. quality of life and self-efficacy).

In view of the known difficulties in measuring the effectiveness of self-management support intervention, we used a mixed-methods design to evaluate both interventions (The RD-app and ZENN intervention). In contrast to the quantitative results, the qualitative result showed that both had an added value for patients. Tailoring was seen as an important mechanism: patients with rheumatic disorders mentioned that the RD-app helped getting more grip on the disease (Chapter 7) and kidney transplant recipients described that the intervention helped them to develop problem-solving skills (Chapter 8). Other working mechanisms of the ZENN intervention mentioned by kidney transplant recipient were: open assessment of one's broad support needs, activation, building confidence and motivation, goal setting, solution focused approach, shared-decision making, and follow-up. The conversational tool (Self-Management Web) helped nurses engage in deeper conversations with their patients in a more structured way. Similar results were found in another study in the NURSE-CC research program, with patients with head and neck cancer. Our self-management support intervention has a unique composition, which has never been tested elsewhere.

The most difficult and perhaps the most important challenge of our mixed-method research was integrating and evaluating the quantitative and qualitative outcomes (Chapters 7 & 8). This has been acknowledged in previous research (Reams & Twale, 2008; van Staa, 2011). Within the paradigm of evidence based practice it would be customary to value the quantitative results as more important (Mantzoukas, 2008). Nevertheless, as paying attention to a patient's individual experiences will increase the quality of care (van de Bovenkamp & Zuiderent-Jerak, 2015), a plea has been made for 'context-based practice' instead of evidence-based practice (Raad voor Volksgezondheid en Samenleving, 2017). This does not imply that qualitative research is more valuable than randomised clinical trials. When testing medical procedures or medication, clinical trials are far more reliable. But in healthcare research, for example on nursing innovations, this kind of research is not always applicable. For one thing, it is not always possible to blind patients and nurses for the intervention or changes in standard care. Although effectiveness of innovations in nursing care cannot always be demonstrated quantitatively, changes can be of great value for patients. Often these innovations lead to better perceived quality of care from the patient's perspective (Chapter 8). Alternatively, by selecting outcome measures that are more closely related to the patient and the intervention, we may be able to detect changes. For example, if we had asked the patients in our study before and after completing the intervention to rate on a VAS scale (1-10) the extent to which they reached their set goals compared to their self-confidence, we might have measured progress. Or by asking questions such as: "Did the intervention have added value for you in comparison with the standard care?", "Do you recommend this type of care for other patients?" and "Do you think the intervention should be included in the standard care provision", we might have been able to gain more insight into the added value of the self-management intervention for patients and the quality of care.

The above considerations call for a change of perspective in researchers, healthcare professionals and policy makers. Not only 'hard' evidence should be used to measure improvements of quality of delivered care, but we should place more importance on patients' and professionals' opinions of what constitutes high-quality care. Nowadays, healthcare institutions increasingly use what are known as patient reported outcome measures (PROMs) by to gain insight into patients' experiences with delivered care (e.g. how much pain was felt after a certain treatment). Besides PROMs, healthcare institutions are recommended to use patients reported experience measures (PREMs) to measure the quality of the delivered care. In contrast to PROMs, PREMs measure what kind of care professionals delivered and whether the patient was satisfied with this care (e.g. Did the nurse listen to you?) (Bos, Zuidgeest, van Kessel, & de Boer, 2015). In our evaluation studies (Chapters 7 & 8), a subscale of an international PREM scale, the Consumer Assessment of Healthcare Providers and Systems (CAPHS), was used to measure patients' experiences with the self-management support intervention. The results

indicated a significant increase in the perceived quality of patient-centred nursing care within the intervention group (T0-T1) (Chapter 8). From both the patients' and professionals' perspective we could conclude that our self-management support intervention was successful and helpful for patients with a chronic condition to deal with daily life challenges. It would thus be a shame if the intervention would not be used in current nursing chronic care due the lack of hard evidence.

Conclusion 4: To detect the added value of innovative self-management interventions, evaluation studies should place more importance on patients' and professionals' opinions of what constitutes high-quality care.

General discussion

In this thesis, we focused specifically on self-management support provided by nurses. It has been advocated, however, that self-management support should be a multidisciplinary team approach (World Health Organization, 2002). Patients in our studies (Chapters 3 & 4) indicated – in line with conclusions from another study in the NURSE-CC research program (Dwarswaard et al., 2016) – a need for professional support, which can be provided by nurses, physicians or other healthcare professionals. However, patients were more inclined to discuss these daily life issues with a nurse because nurses were less pressed for time. These findings are congruent with previous research about patients' preference to discuss medical care with the doctor and receive additional support from a nurse or NP (Laurant et al., 2008).

Lack of time is often mentioned as an obstacle to provide healthcare care with a biopsychosocial focus (Chapters 2 & 8). But is providing biopsychosocial care always more time consuming? A self-management support intervention such as the ZENN intervention indeed requires more consultation time. Nurses in our study had 30 minutes' consultation time instead of the usual 15 minutes. In today's healthcare system, it seems not realistic to expect doctors to extend their consultation sessions. On the other hand, it seems reasonable to expect a doctor to inform about a patient's daily life with a chronic condition and this does not always have to be more time consuming. Consequently, given that nurses are highly trusted by their patients and trained to provide patient-centred care, nurses are in an excellent position to provide support tailored to the specific needs assessed by a doctor. The doctor's role as a medical expert is not a problem; it is important, though, that even the doctor recognises their patients' holistic support needs . Good cooperation and multidisciplinary team work in self-management support (e.g. between doctors, nurses and patients) contributes to a more effective and patient-centred healthcare system (Babiker et al., 2014; Baker, Gustafson, Beaubien, Salas, & Barach, 2006).

TO CONCLUDE….

How can nurses effectively support patients like Mark in the self-management challenges of dealing with their chronic condition(s) in daily life?

People with chronic conditions (like Mark in the case in Chapter 1) wish to receive self-management support from professionals that fits their needs, does not have a limited (biomedical) focus and that addresses all daily life areas that are challenged by their condition(s). Standardised education provision is not sufficient to enable them to deal with their chronic condition in daily life. From Mark's point of view, his nurse would bring added value by regularly assessing the challenges of his everyday life (such as work, relationships, financial aspects, adherence to therapy). Only then, nurses can facilitate developing the problem-solving skills a patient needs to live a satisfactory life despite the illness.

FUTURE DIRECTIONS

Recommendations for clinical practice

- From the patients' point of view, all healthcare professionals should understand the importance of providing self-management support from a broad perspective. Nurses, then, should more often provide self-management support from such a broad perspective. To achieve this, nurses should get a sense of the necessity of providing holistic, tailored support to outpatients with a chronic condition.
- Nurses need to acquire self-management support competencies in line with the phases of the Five A's model: assessing, advice, agree, assist and arrange. In all phases, nurses should strive to form partnership with their patients.
- Nurses, and other healthcare professionals, should refrain from providing solely education to promote their patient's self-management behaviour. They should use interventions that focus on improving patient's intrinsic processes like self-efficacy and motivation. Using conversational tools, such as the 'Self-management Web', can help them to identify and assess a patient's individual support needs. In addition, practical self-management interventions that enable nurses to coach a patient's self-management should be implemented.
- Nurses and other healthcare professionals should cooperate more often in providing self-management support: a multi-disciplinary approach is required.

Recommendations for future research

- Future research should continue with evaluating the open, tailored and holistic self-management support intervention, provided to patients with various types of chronic condition. It would be encouraging to choose outcome measures closely related to the patient and intervention. More importance should be given to pa-

tients' and professionals' opinions about the added value of interventions aimed to improve the quality of care.

- In current research articles, it is not clear to what components of an intervention success or failure can be ascribed, for whom these interventions work and in what circumstances. Researchers should not only evaluate the effectiveness of interventions but explain working mechanisms by using mixed-method designs.

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