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General Discussion
Although a rising number of end stage renal disease patients undergoes renal transplantation, a substantial group of patients depends on dialysis in order to survive. In 2019, 35% of the population receiving renal replacement therapy in the Netherlands underwent dialysis (Nefrodata, 2019). Previous psychological research has shown the possible detrimental effects of dialysis, such as impaired quality of life and well-being (Abdel-Kader, Unruh, & Weisbord, 2009). Individuals on dialysis also report a reduced sense of autonomy in their lives (Jansen, Rijken, Heijmans, & Boeschoten, 2010). Specifically, they experience lower control over their illness and treatment compared to transplanted patients, which has in turn been related to decreased well-being and quality of life (Griva, Jayasena, Davenport, Harrison, & Newman, 2009). Up till now, no psychosocial intervention exists for enhancing perceptions of control in people on dialysis. The aim of this thesis was to better understand dialysis patients’ experience of control and to develop and evaluate an intervention for enhancing perceived control.

The preceding chapters described the results of this process in three studies: 1) a prospective study examining the factors associated with improved well-being from pre- to post-transplantation 2) a qualitative study in the preparation phase of the psychosocial intervention, examining the meaning, facilitators and barriers impeding a sense of perceived control and 3) a randomized controlled trial (RCT) aimed at examining the effectiveness, feasibility and acceptability of a psychosocial self-regulation intervention for enhancing perceptions of control in people undergoing dialysis. This last chapter will provide an overview of the main findings, explore methodological considerations and provide a critical reflection on the clinical implications and recommendations emanating from this thesis. To conclude, some suggestions will be given for future research.

**Main findings**

In the first part, we focused on how self-regulation processes and benefit finding relate to distress in individuals with end stage renal disease from pre- to post-transplantation. Self-regulation is a widely studied psychological mechanism, referring to the complex interplay of cognitive, emotional and behavioural factors aimed at reaching one’s life goals (Bandura, 1977). Self-regulation has mainly been studied in the context of health decline, showing that a confrontation with severe illness can disturb the pursuit and attainment of important life goals, consequently leading to decreased well-being. However, it is not known whether this theory can also be applied the other way around: i.e. if a health improvement reduces goal disturbances and whether this is associated with increased well-being. **Chapter 2** attempts to contribute to this knowledge gap by examining goal disturbance changes from before to after renal transplantation and its association with psychological distress over time. In addition, the possible mediating role of
perceived control was studied. Before transplantation, approximately 30% of the patients encountered high to very high goal disturbance. The most disturbed goals before transplantation pertained to disease-specific goals, such as being able to eat or drink what one likes. This did not correspond with the most important goals before transplantation, mainly belonging to the interpersonal domain, such as having relationships characterized by mutual trust. Goal disturbance generally decreased from before to after renal transplantation and this decrease was related to reduced psychological distress. Rather than perceived control mediating the relationship between reduced goal disturbance and reduced distress, we found that an increase in perceived control was independently associated with a decrease in distress from pre- to post-transplantation. Overall, these findings underscore the importance of reductions in goal disturbance and increased perceived control, contributing to improved well-being, allowing for intervention recommendations.

Another concept that has not been studied in the process of a health improvement is benefit finding. Benefit finding (BF) refers to the capacity to identify positive psychological changes following a traumatic life event, such as the diagnosis of severe illness (Tedeschi & Calhoun, 2004). This paper contributed to the existing gap in the literature by examining changes in benefit finding in the course of a positive health change; i.e. renal transplantation (Chapter 3). Over time, BF increased from before to after renal transplantation. These findings challenge the notion that benefit finding uniquely occurs when facing an adverse life event (Tedeschi & Calhoun, 2004) and support our idea that a positive medical intervention aimed at improving overall mental and physical health, such as transplantation, can foster the identification of benefits over one’s illness. Given the longitudinal nature of the study, we were also able to look at the relation over time between benefit finding and distress. Interestingly, the relation between benefit finding and distress changed over time. That is, distress before transplantation predicted an increase in benefit finding after transplantation, whereas after transplantation, distress predicted a subsequent decrease in benefit finding. Our findings stress the importance of future longitudinal research in disentangling the relation between benefit finding and indicators of well-being.

We further explored the concept of perceived control in the second part of the thesis. Previous research repeatedly found that perceiving control over one’s life is essential for successful aging, particularly when facing health decline (Gerstorf et al., 2014; Infurna, Gerstorf, Ram, Schupp, & Wagner, 2011). Perceiving control over one’s illness is associated with better quality of life in end stage renal disease patients (Griva et al., 2009). This has instigated a recent emphasis on perceived control and related concepts (such as self-efficacy) in dialysis patients through health care programs stressing patients’ responsibility and illness
management (Hudson, Moss-Morris, Game, Carroll, & Chilcot, 2016; Karadag, 2019; Pungchompoo, Parinyajittha, Pungchompoo, & Kumtan, 2020). Nevertheless, perceived control remains an abstract term mainly used in the empirical literature. No research has looked at the way dialysis patients themselves think about perceived control, whereas such information is vital to offer understandable and desired psychosocial care. Chapter 4 looked at the meaning of perceived control, factors supporting control and factors impeding a sense of control from a patients’ perspective using qualitative methodology. Findings overall indicated that the term perceived control is multi-dimensional; not only pertaining to the belief but also including behaviours to successfully exercise control, as well as factors referring to one’s identity, such as being positive and grateful. The level of experienced control differs according to the domain on which perceived control is assessed (e.g. dialysis treatment, finances, health, work, social contact or intimate relationship) and on the level of abstraction that people employed (global or specific). Facilitators of perceiving control included adaptive coping, shared decision making, and adherence to lifestyle changes. Barriers of perceiving control were constituted by feelings of dependence, an experienced lack of shared decision making and type of dialysis (center dialysis as opposed to home dialysis). These findings offer practical and applicable guidelines for the development of a psychosocial intervention enhancing perceptions of control, for example by enhancing adaptive coping strategies or supporting patients to make decisions together with their care providers.

Based on previous findings that a lack of autonomy (including perceived control) is a commonly reported problem by dialysis patients (Jansen et al., 2010) and that self-regulatory skills are essential for maintaining a sense of control over life and overall well-being (Wrosch, Scheier, Miller, Schulz, & Carver, 2003), we developed a psychosocial intervention based on self-regulation theory as a mean to optimize a sense of control and well-being. Specifically, the intervention was aimed at providing self-regulatory tools for adaptive goal adjustment, such as letting go of unattainable goals and replace these goals with more attainable and important life goals (Janse et al., 2016). Chapter 5 described the content of the intervention and the design of the randomized controlled trial (RCT) aimed at studying its effectiveness, feasibility and acceptability.

The last part of the thesis consisted of the examination of the psychosocial intervention, specifically reporting the preliminary effectiveness, feasibility and acceptability of the intervention. Chapter 6 reports on the findings of the randomized controlled trial. Although recruitment rate was low, these preliminary findings point towards the preliminary effectiveness of the psychosocial intervention, given the greater improvements in perceived control and well-being in the intervention group compared to the control group. In addition, according to
participants, the intervention was feasible, acceptable and useful. For example, participants indicated that it raised a sense of awareness of what is considered important in life. The use of jargon was considered a difficult aspect in the training, hereby underscoring the importance of providing comprehensible information to people on dialysis when offering psychosocial help.

The finding that a very low proportion of patients enrolled in an intervention trial that complied with rigorous methodological study standards, has also been reported in other studies in somatically ill patients (Hudson et al., 2017; Mosher et al., 2014; van der Donk et al., 2019). Gaining a deeper understanding on the reasons for not accepting care and the characteristics of those patients eligible for trial participation but not wanting care, could further inform clinical practice. Therefore Chapter 7 examined the proportion and characteristics of patients with low perceived control, and subsequently the proportion and characteristics of these patients who did not accept care and the reasons for not accepting care in the context of the RCT. 55% of the 430 screened patients reported low perceived control. More comorbidities and experienced problems in daily living were related to low perceived control. Over 90% of the patients with low perceived control did not accept psychosocial care for regaining control, especially older patients. The main reason for not accepting care was perceiving no burden (40%). A possible reason for not perceiving a burden could be that patients are not aware of the signs of low perceived control. For example, the feeling that one is not able to solve their problems (Pearlin & Schooler, 1978). Hence, informing dialysis patients about the signs and consequences of low perceived control might encourage them to accept psychosocial care for regaining control.

In conclusion, findings in the first part of the thesis indicate that self-regulation processes and benefit finding are two mechanisms underlying improvements in well-being from pre- to post- renal transplantation. Findings from the second part of the thesis (focusing on perceived control) showed that according to a patients’ perspective, perceived control is a complex and multi-dimensional concept. Lastly, the psychosocial intervention based on the principles of self-regulation theory was preliminary effective, feasible and acceptable for regaining perceived control in people on dialysis with low perceived control.

Methodological considerations: strengths and limitations

Study design
The findings presented in the previous chapters should be interpreted in the light of their strengths and limitations. Three strengths with respect to the study design can be noted.
First, the strength of the study is its mixed methods design (Chapter 4 and 6), in which findings from (previous) quantitative findings could further be explored and corroborated by means of qualitative interviews. In psychology, the added value of qualitative methodology alongside quantitative methodology is increasingly acknowledged. Especially because qualitative methodology has an important contribution in exploring opinions, perceptions and needs of individual patients and provides a rich insight in the meaning that people attribute to (inner) experiences and events (Rohleder & Lyons, 2015).

Second, Chapters 2 and 3 had a prospective design with one assessment before transplantation and 3, 6 and 12 months after renal transplantation. Overall, such a prospective study has substantial benefits in terms of being able to look at changes within individuals over time and identifying factors related to such changes, as opposed to for example a cross-sectional design.

Third, in Chapter 6, the effectiveness, feasibility and acceptability of the psychosocial intervention for enhancing perceived control was examined with a multicentre randomized controlled trial (RCT), following the strict CONSORT criteria for adequate reporting of RCTs. This design is considered the golden standard within intervention research because it minimises confounding and it can make causal inferences.

Some limitations should also be acknowledged. First, qualitative methodology is descriptive in nature and informs us about the experiences, opinions and needs of the current study sample. Study results can therefore not be generalized to the broader dialysis population. The findings of the qualitative study might further be corroborated and explored in the future with quantitative methods. For example, by examining the statistical relation between different coping strategies and shared decision making with perceived control in people on dialysis. These results might further inform the development of interventions to enhance perceived control in individuals on dialysis.

Second, the prospective study design used in Chapter 2 and 3 cannot make causal inferences, which would require the random allocation of patients to a transplantation or a waitinglist control condition. However, for obvious ethical and practical reasons such a study design is not possible. Therefore, we cannot be sure whether changes observed from pre to post-transplantation and the relations with other variables are due to the transplantation or could be explained by another third variable.

Third, the randomized controlled trial as described in Chapter 6 also presents limitations. Conducting a randomized controlled trial is very time-consuming and
General Discussion

requires a lot of resources, given the demand for a large sample size and multiple study sites. The strict in- and exclusion criteria and highly controlled setting can also limit external validity of the findings. Other kinds of study designs might also be considered in the future, such as ecological momentary assessments (EMA), in which repeated measurements can be collected within the same persons. Advantages of such a design is that it requires fewer participants compared to an RCT, it improves ecological validity and it can capture fluctuations in the outcome measure over time (Shiffman, Stone, & Hufford, 2008).

Samples
A major strength of this thesis was the large sample size of individuals with end stage renal disease on the waiting list for renal transplantation who received a kidney transplant (Chapter 2 and 3). Other strengths of this thesis include the systematic assessment of in- and exclusion criteria for trial participation as well as the screening for low perceived control in all patients dialyzing in the participating dialysis centres. As a consequence, it was possible to assess the prevalence of low perceived control in a substantial sample and report on the characteristics of patients with low perceived control, as well as to gain insight in the characteristics and reasons for patients to not accept care for regaining control, as described in Chapter 7. This offers a significant contribution to the current literature, because information on the characteristics of non-responders in intervention research is largely lacking.

Limitations of the study samples should also be acknowledged. First, in the qualitative study on the meaning, facilitators and barriers of perceived control (Chapter 4), participants were recruited via the patient organization of the Dutch Kidney foundation. These patients were active members of the organization and willing and able to talk about perceived control. They might not be representative for the overall dialysis population, especially because this view of “active” patients may not correspond with the dominant clinical observation of care professionals of the “hospitalized” patients; that is, patients who have been in a medical setting for a long period of time and therefore seem more passive and less involved in their treatment. Future research might apply different kinds of qualitative data collection methods, for example my means of participant observation, in-depth individual interviews and focus groups. Eventually, this may lead to a rich and comprehensive account of the topic of perceived control in the dialysis context.

Second, results might not generalize to the overall dialysis population given that patients who wanted to participate in the trial and thus accepted care for regaining control, were significantly younger compared to the ones who did not accept care (Chapter 7). The finding that younger patients are more inclined to accept care is supported by other research (Mosher et al., 2014). This is of special importance
in light of the current trend whereby the dialysis population is becoming older and suffers from more physical complications given the increasing number of transplantations that are being performed on patients who would have previously been considered ineligible for transplantation (Kiberd, Boudreault, Bhan, & Panek, 2006; Lenihan, Hurley, & Tan, 2013). The question raised by this study is therefore what kind of help is desired according to older people on dialysis with low perceived control. A recent qualitative study conducted by our research team in dialysis patients with low perceived control who declined care for regaining control (data not published) showed that some people on dialysis attach more importance to the practical issues surrounding the dialysis treatment, such as transportation arrangements or adequate housing. Future research might further clarify the needs for care among older people on dialysis with low perceived control and ways in which their care needs can be adequately addressed.

Third, a particular time- and labour-consuming aspect within the RCT is the process of patient recruitment, which entails the selection of eligible participants for trial inclusion and is also referred to as sampling. In our study, consecutive sampling for trial inclusion was used, which means that all patients in the participating dialysis centres were screened for low perceived control. Although consecutive sampling is considered the golden standard in controlling sampling bias, only a small percentage of participants eventually enrolled in the trial, therefore questioning its effectiveness. Future studies might consider other types of sampling, such as a convenience sampling. Within convenience sampling, patients are referred (by themselves or by a health care professional) to the intervention and then assessed on trial eligibility. Advantages of convenience sampling include lower costs, less resources and higher efficiency.

Clinical implications and recommendations for future research
Given that low perceived control is prevalent among people on dialysis and no intervention is available for enhancing control perceptions yet, this thesis focused on the development and evaluation of such an intervention in the context of dialysis, given the potential important contribution to clinical practice. Clinical implications and recommendations based on the findings of this thesis will be presented in the next section.

Improving acceptance of psychosocial care for enhancing perceived control
In the multi-center randomized controlled trial (Chapter 5), approximately 90% of the eligible patients with low perceived control declined care for enhancing perceptions of control within the intervention study. Importantly, only 5% of participants declined the intervention because they did not want to participate in research, which suggests that the research context was not considered a barrier for participation (e.g. randomization, filling in questionnaires). The most frequent
reported reason for declining care was perceiving no burden (40%). However, perceiving no burden remains a broad reason for not accepting care and could also include other reasons, such as having resigned or accepted the situation in which little control is experienced, or a feeling of demoralisation, characterized by feelings of meaninglessness and hopelessness regarding the future (Kissane, 2001). Another possible reason for not perceiving a burden might be that people on dialysis do not easily recognize the signs of low perceived control, such as the feeling of not being able to solve problems encountered in life (Pearlin & Schooler, 1978), and therefore do not accept care. This idea is supported by a previous study among dialysis patients suffering from depression and/or anxiety, showing that the unawareness of depression and/or anxiety symptoms was the most prevalent barrier for accepting psychological care (Johnson & Dwyer, 2008).

Therefore, it could be hypothesized that raising awareness on the aspects and consequences of low perceived control, as well as communicating the options for psychosocial treatment and the expected benefits of this treatment, could support patients in accepting care for enhancing perceived control. Information and treatment options for low perceived control could be offered within regular health care, by the responsible nurse or social worker, during routinely visits or the dialysis treatment.

**Recommendations for enhancing perceived control**

In light of the low drop-out rate once in the trial, and the helpful components of the intervention as indicated by the participants, it can be suggested that the intervention for enhancing perceptions of control was overall considered acceptable (Chapter 6). Specifically, the psychosocial intervention increased a sense of awareness of what is important in life and it also helped as a motivator when setting and monitoring important goals. However, this chapter also revealed difficult aspects of the intervention, including the use of jargon.

The problem of jargon use deserves special attention considering the growing number of studies emphasizing low health literacy in chronic kidney disease, including end stage renal disease, and its detrimental effects for patients’ self-care management and health outcomes (Taylor et al., 2016, 2018). Therefore, other kinds of communication methods in the relationship between patient and health care provider could be considered. For example, by means of graphic representations of the concept of perceived control (e.g. letting patients choose a picture that best represents for them a sense of control over life), the use of simple and clear language and regularly assessing patients’ understanding of the given verbal and written information. This is supported by findings of a recent systematic review, showing that easier language improves knowledge and awareness in people with chronic kidney disease with low health literacy (Boonstra et al., 2020). In addition,
as shown in Chapter 4, some patients have a very clear view of what perceived control means to them and what constitutes a sense of control. Once this is made explicit, health care providers might adopt patients’ terminology so that patients feel heard and at ease.

The qualitative study on the factors facilitating and impeding a sense of control (Chapter 4) also offered additional applicable suggestions for enhancing perceptions of control in people on dialysis. Overall, patients reported that adaptive coping, shared decision making and adherence to lifestyle changes contributed to a sense of control. The topics of adaptive coping and adherence to lifestyle changes referred to the way patients themselves deal with their illness and make adaptations in daily life, which was partially targeted within the psychosocial intervention. Shared decision making refers to the relationship between patients and physicians and how they work together in order to provide the optimal treatment for the patient. Interestingly, despite the growing empirical and clinical interest in the concept of shared decision making, patients in our study indicate that they can encounter problems or have questions that are perceived as not always being adequately addressed by their health care team. This finding is for example supported by recent findings showing that only half of the dialysis patients considered their own opinion most important in making treatment decisions (Verberne et al., 2019). This indicates that there is still room for improvement in the shared decision-making process within the dialysis setting. For example, by viewing shared decision-making as a continuous process (instead of one moment in time), and regularly assessing whether the treatment plan still matches the patients’ preferences and values. Future research might shed more light on the association between shared decision-making interventions and perceived control, and its association with well-being and quality of life.

**Timing of care in the CKD trajectory**

Another reason for patients declining care for enhancing perceptions of control could be the period of time they have experienced low perceived control. The average time on dialysis in our RCT was 3.6 years (Chapter 7). It can be expected that perceived control declines from pre-dialysis to dialysis, in light of the high physical and psychological treatment burden of dialysis. This would mean that, in our study context, patients experienced a low level of perceived control for a long period of time before they were offered psychosocial care within the intervention trial. Patients with prolonged low perceived control may feel they cannot change their situation and thus resign to the feeling of low control, or experience it as an irreversible side-effect of dialysis, resulting in the refusal of care for regaining a sense of control. Currently there is no evidence that the initiation of dialysis is directly related to a subsequent decline of perceived control. However, previous research findings show that control beliefs diminish after renal transplant failure.
and thus when dialysis is required (again) (Griva, Davenport, Harrison, & Newman, 2012). Furthermore, there is evidence in the opposite direction: renal transplantation (i.e. discontinuing dialysis) is related to an increase in perceived control (Schulz et al., 2017). These findings support our idea that the initiation of dialysis is related to a subsequent decrease in perceived control.

The abovementioned raises intriguing questions regarding the timing of psychosocial care. In case patients experience a pronounced decline of perceived control after the start of dialysis, they might experience a higher burden and be more receptive to psychosocial care for regaining control during that period. It may even be suggested that patients could benefit from psychosocial care in the pre-dialysis phase, so as to prepare and prevent for radical declines in perceived control in the dialysis stage. For example, by offering information on the detrimental effects of low perceived control and provide practical tools for remaining or increasing a sense of control for when initiating dialysis, by means of self-management skills or adaptive coping strategies. This hypothesis is however speculative because people on dialysis could also experience more difficulties and a higher psychological burden over time. Further research is required to investigate the changes in perceived control and psychological burden from pre-dialysis to dialysis and the appropriate timing of psychosocial care.

**Aligning care to care needs of dialysis patients**

Overall, this thesis shows that reporting low perceived control does not necessarily equal a need for care in people undergoing dialysis. This mismatch has also been reported in other studies in the field of nephrology (Hudson et al., 2017). This thesis stresses the importance of aligning psychosocial care to the personal care needs and preferences of people on dialysis, considering the interplay between asking what patients want and offering information and advice. Asking dialysis patients about their view on perceived control, what they find important in life, what hindrances they experience in different life domains and how they would like to engage in their treatment might be relevant. Health care providers might offer information on the detrimental effects of low perceived control and discuss treatment options in clear and simple language within regular health care.

Hopefully, the research findings presented in this thesis will be an important step in improving the uptake of desired and acceptable care of dialysis patients, improving their perceived control and eventually fostering well-being and quality of life.
References


Chapter 8


