CHAPTER 7

General discussion
The goal of this thesis was to investigate innovative psychosocial care for HNC and LC patients with symptoms of anxiety and depression. Studied topics were prevalence of depression, screening for distress, stepped care, and self-management and eHealth. In this final chapter, the main findings are summarized. Subsequently, the main findings are discussed in relation to prior research. Clinical implications are addressed and suggestions for future research are provided. This chapter is completed with a general conclusion.

SUMMARY OF THE MAIN FINDINGS

Prevalence of depression in cancer survivors during or after treatment ranged between 8% and 24% and depended on the instruments used, type of cancer and treatment phase (Chapter 2). Among HNC patients, screening for distress appeared to have added value because of the patients who screened positive for psychological distress (29%), the majority (82%) did not yet receive treatment (Chapter 3). Stepped care consisting of (i) watchful waiting (2 weeks), (ii) guided self-help (5 weeks) via the Internet or a booklet, (iii) problem-solving therapy delivered by a nurse, and (iv) psychotherapy or psychotropic medication, was found to be effective to reduce distress and improve HRQOL among HNC and possibly LC patients with untreated psychological distress (Chapter 5).

With respect to step 2 of the stepped care program, reasons to start a guided self-help intervention were intrinsic (e.g., to help oneself) and extrinsic (e.g., being asked by a care professional or to help improve health care). Although some patients felt the intervention had brought them nothing or indicated that they felt worse temporarily, most participants perceived positive outcomes of the intervention such as feeling less distressed and having learned what matters in life (Chapter 6).

DISCUSSION OF THE MAIN FINDINGS

SCREENING FOR PSYCHOLOGICAL DISTRESS

Nowadays, both national and international cancer institutions widely recommend the assessment and treatment of psychosocial distress in routine cancer care as a quality care standard. In the study on the added value of screening for psychological distress among HNC patients it was concluded that screening for psychological distress was beneficial because nearly one third of patients who screened positive for psychological distress did not yet receive treatment (Chapter 3). Interestingly enough, the stepped care
trial showed that 28% of patients in the intervention group had recovered after two weeks of watchful waiting, that is two weeks after screening (step 1) (Chapter 5). It may be that the distress of these patients resolved spontaneously after reassurance in the medical follow-up consultation that malignancy had not recurred, which consultation occurred at the same day as screening for distress. Another explanation might be that offering distressed cancer patients the chance to discuss their distress after screening plus the prospect of getting psychosocial help makes a substantial contribution to their well-being. In a large clinical trial on the efficacy of screening for psychological distress by Carlson et al.5, 585 patients with breast cancer and 549 patients with lung cancer were randomized to one of three conditions, including (i) minimal screening, in which only the Distress Thermometer was administered without feedback to the patient or clinician; (ii) full screening with multiple questionnaires, followed by a printed personalized feedback report and a summary report that that was included in the patient’s medical file; and (iii) full screening as described above plus an optional personalized phone triage with referral to resources. Similar to the finding in the RCT as presented in this thesis, the authors reported that the patients who were offered a chance to discuss their psychosocial issues with a staff member followed by triage to appropriate resources demonstrated a larger decrease in distress at 3 months follow up than those patients who received screening only. However, whether the decrease in distress was induced by the offered psychosocial care, or by the referral itself was not investigated.

Although screening for psychological distress via OncoQuest is valued by the coordinating staff and by patients, not all eligible patients made use of OncoQuest. A mixed method study including qualitative and quantitative research measures is ongoing and will provide detailed insight into possible barriers and facilitators among patients as well as care providers. The results of this study will also enable further optimization of OncoQuest in clinical practice. OncoQuest is a tool to facilitate communication between patient and care provider (in the RCT as presented in this thesis: a nurse) and can be seen as a quick scan of health related quality of life. Obviously, OncoQuest does not comprise all possible health related quality of life issues that patients may encounter, because it consists of only three patient-reported outcome measures (the EORTC QLQ-C30, the EORTC tumor-specific module, and the HADS). Also, the program does not include an open question on the need for supportive care such as “What kind of supportive care would you like?”. Therefore, it is crucial to combine OncoQuest with a consultation with a nurse who can discuss the results of OncoQuest more in-depth with the patient. For
example, many patients who do not reach screening criteria for psychological distress do want psychological help6-8, and vice versa patients who do reach screening criteria may need explanation on the benefit of psychosocial care to help them to decide. Another example refers to Salander et al.9 who found that a substantial part of cancer patients want help for interpersonal or existential issues that might not be identified by the HADS or EORTC questionnaires embedded in OncoQuest. Perhaps exchanging the diagnostic framework for screening, in which health need is indicated by the presence of a psychological disorder, for a framework in which health need is identified from multiple perspectives, is recommendable10. Further research is needed to advance knowledge about the most effective implementation strategies in the context of cancer care11.

ORGANIZATION OF CARE

The Institute of Medicine (IOM) Report entitled Cancer Care for the Whole Patient published in 200812 recommended that cancer care includes the provision of appropriate integrated psychosocial care. Integrated care refers to a system of care in which all the services needed to treat the patient are combined in a way that makes them accessible for the patient who needs these services. It should include identification of psychosocial care needs, a plan to address these needs, routes to connect patients with psychosocial care services, support of self-management, and follow-up on provided care12. In their adaptation of the Pan-Canadian Practice Guideline on Screening, Assessment, and Care of Psychosocial Distress (Depression, Anxiety) in Adults With Cancer13, Andersen et al.3 recommended in 2014 that all patients with cancer should be evaluated for symptoms of depression and anxiety at periodic times across the trajectory of care, using validated, published measures (such as the HADS) and procedures. An integrated care model has shown to be (cost-)effective to treat depression in an oncologic setting is collaborative care14-16. The collaborative care model was originally developed to improve management of depression in primary care: a psychiatrist and a care manager collaborate with the patient’s primary care physician to provide systematic, hands-on treatment and follow-up17. The model emphasizes three core concepts: population-based care (improving the quality of care and outcomes of defined populations with chronic illness), measurement-based care (including tracking systems and timely measurements of disease control), and stepped care18. In stepped care, the primary focus is on psychological interventions of increasing intensity and expense. In a recent meta-analysis and review of all randomized trials on stepped care for depression, van Straten et al.19 discussed that there is only
limited evidence to recommend stepped care above alternative systems. They could not draw firm conclusions, because they found considerable variety in the implementation of the stepped care programs. For instance, the majority of included trials did not provide a program with progressive increase in treatment intensity. The RCT as reported on in this thesis showed that, a ‘true’ stepped care program, including increasing treatment intensity, was effective in reducing distress and improving health related QOL among HNC and possibly LC patients with untreated psychological distress compared with care as usual. One could argue that the care as usual in the trial as presented in this thesis was no ‘true’ care as usual, because an active approach was used to recruit and select patients. Before being asked to participate, patients were screened for distress, eligible patients were made aware of their HADS score by a researcher, and psychosocial issues were discussed. The awareness, insight and attention given by the researcher may have positively influenced feelings, thoughts and behavior among patients in both intervention group and care as usual group. Nevertheless, the stepped care program proved to be effective.

It would be interesting to compare the stepped care program with a similar care program, such as “Depression Care for People with Cancer” (DCPC). DCPC is an integrated collaborative care program targeting major depression in patients with cancer, which has been found to be (cost-)effective in the SMaRT Oncology trials. The main difference between DCPC and the stepped care program as presented in this thesis is that the latter starts with watchful waiting and a self-help course, as where DCPC directly starts with face-to-face sessions with a specialized nurse.

To make matters clear, the findings of this thesis fortify the current opinion that decisions about psychosocial treatment provision should be followed up systematically in cancer care, and that changes should be made if current treatments do not achieve a substantial health improvement.

SELF-MANAGEMENT AND EHEALTH

Self-management support has been identified as an opportunity to improve health outcomes in cancer care. Health care interventions, including self-management support, are increasingly being delivered through the Internet. The Internet is a practical, cost-effective, widely accessible medium with the ability to provide customized information and support. Internet interventions have the potential to fill an important gap in quality cancer care by augmenting limited available mental health services. Also, Internet
interventions create greater privacy and confidentiality. Patients can seek treatment at home at their convenience, an important aspect for patients reluctant to frequent medical appointments and the stigma associated with the receipt of psychological therapy. Though web-based (eHealth) self-management interventions can reduce symptoms of depression and anxiety, and improve overall quality of life among cancer patients, evidence-based (eHealth) self-management interventions targeting psychological distress in HNC and LC patients are scarce. The results of the RCT as presented in this thesis showed that a guided self-help intervention via the Internet or a booklet for HNC and possibly LC patients with psychological distress as part of the stepped care program is effective compared with care as usual, and seems to be welcomed by cancer patients. The qualitative analysis in this thesis of the self-help intervention showed that, though most, but not all, reported the intervention to be beneficial. Incorporating a motivational interview prior to start of the intervention and tailoring the intervention and coaching sessions to patients’ individual needs might improve the beneficial effects of the self-help intervention. Patients who are actively engaged in their treatment may be more likely to retain, and use newly learned techniques - effects possibly mediated through greater self-efficacy.

**CLINICAL IMPLICATIONS**

With the increasing number of cancer patients in the coming decades, the demand for psychosocial support will rise equally. The Dutch Society for Psychosocial Oncology (Nederlandse Vereniging voor Psychosociale Oncologie, NVPO), Netherlands Comprehensive Cancer Organisation (Integraal Kankercentrum Nederland, IKNL) and the Dutch Cancer Society (KWF Kankerbestrijding) have together developed a multidisciplinary, evidence-based guideline called ‘Screening for psychosocial distress’. The guideline should support care providers in providing integrated psychosocial care to the patient with cancer. Identifying psychological distress, discussing it with the patient and referral to specialized psychosocial care, if necessary, form part of this integrated care. The findings from the present thesis strengthen the recommendations presented in the Dutch guideline. Routine screening for psychological distress in patients with cancer is crucial (via the Distress Thermometer as recommended in the Dutch guideline or, for instance, via the HADS in OncoQuest) at key points in the disease journey. When psychological distress is identified, ideally an (specialized) oncology nurse of the treating team should
take responsibility for coordinating proper assessment, referral and follow-up. A stepped care model is proposed, starting with the least (cost-)intensive intervention available that is still likely to provide a significant health gain. The results of treatment are monitored systematically, and changes are made (‘stepping up’) if the current intervention is insufficient in improving health. Each cancer facility should identify their own referral system based on the current care structure and local health resources, as well as patients’ preference. Feedback of the content and results of the provided supportive care to the cancer care provider and the primary care provider is a vital element of multidisciplinary integrated care.

RECOMMENDATIONS FOR FUTURE RESEARCH

As currently routine screening for psychosocial distress in cancer care is recommended as a quality care standard, screening through the Internet may be a way to increase access and convenience, save time and space, and reduce costs in the often busy oncological clinics. The Internet provides the ability to make OncoQuest (or the Distress Thermometer) available for patients at home and share their results with all involved care providers. OncoQuest is considered as a quick assessment of quality of life, which facilitates communication between patient and care provider on quality of life issues. Another approach is the development of a self-management application called Oncokompas2.0, an integrated eHealth application to monitor health related quality of life, to provide personalized information on quality of life and supportive care, and to support cancer survivors by finding and obtaining optimal supportive care, adjusted to their personal health status and preferences. OncoKompas2.0 comprises a generic module for all cancer survivors, targeting healthy lifestyle (smoking, alcohol use, exercising, nutrition, weight, stress), physical functioning (pain, sexuality, sleep, fatigue, body image, diarrhoea, constipation, hearing, loss of appetite, nausea/vomiting, neuropathy, lymph edema, functioning in daily living), psychological functioning (anxiety, depression, fear of recurrence, cognitive functioning), social functioning (social life/loneliness, relationships, relation with children, financial issues, return to work, communication with care providers), and existential issues (meaning, religion, future perspectives). Furthermore tumor-specific modules will be available, for example for head and neck cancer patients (swallowing, speech, oral function, neck and shoulder function, tube feeding, loss of smell and taste). All patients receive tailored information
on their lifestyle, their physical, psychological, and social functioning, and existential issues; patients with minor problems are informed on self-help interventions, and on professional care in case of major problems. Further research is needed (and ongoing) on the (cost-)effectiveness of Oncokompas2.0, including the stepped care approach build into this self-management application.

Treating numerous patients with inappropriate low-intensity interventions that are not beneficial for part of them is a waste of money, time, and impacts the quality of life of patients. Therefore, taking the stepped care program from an experimental phase to routine cancer care practice, further research is needed to predict whether a patient can follow the entire stepped care model or needs to skip a step, based on which stepped care can be further tailored towards a personalized stepped care approach. Also, more studies should be carried out to demonstrate the cost-effectiveness of stepped care in oncological settings. Future research can create an evidence-based blueprint for implementation of stepped care in clinical practice, including crucial determinants of effectiveness. Meta-regression and qualitative analyses may be useful in dismantling active ingredients in complex intervention models like stepped care.

Further, though web-based (eHealth) self-management interventions can reduce symptoms of depression and anxiety, and improve overall quality of life among cancer patients, not all patients perceived positive experiences and outcomes. Future research should identify patients who might benefit most from (web-based) self-management targeting psychological distress.

In multicultural countries like the Netherlands, (web-based) self-help interventions have the advantage that they can easily be translated into different languages, further increasing access to supportive cancer care also among ethnic minorities. And, as the Internet evolves, in the future, interaction between coach and participant as part of web-based guided self-help interventions can be improved through synchronous (real-time) audio-video communication (e.g., video chat programs such as Skype or Facetime). This type of communication closely resembles face-to-face contact and gives access to essential face-to-face signals such as intonation, facial expressions, and body language. Through live guidance, the coach may be able to offer more personalized feedback. In addition, this type of contact may facilitate feelings of accountability and social support, higher engagement, an improvement of the therapeutic bond, and reduce the risk of misinterpretations, compared with e-mails and text messages.
Chapter 7

CONCLUSION

The prevalence and impact of depression and anxiety in cancer patients demand optimization of access to mental health interventions, urging the health care system to develop and employ (cost-)effective programs. A stepped care program proved to be effective in reducing psychological distress and improving HRQOL among HNC and possibly LC patients. Furthermore, screening for distress is important and should be part of clinical cancer care. It is indispensable that the results of treatment and the decisions about treatment provision are monitored systematically, and that changes are made (‘stepping up’) if current treatments do not achieve a significant health gain.
REFERENCES


