SUMMARY
Chapter 1 comprised the general introduction of this thesis. The focus in this thesis was on head and neck cancer (HNC) and lung cancer (LC) patients. A description of these cancer types and their treatment options is given and the impact on quality of life. Symptoms of depression and anxiety (psychological distress) are highly prevalent in cancer patients. Though psychological interventions have proven to be effective in cancer patients, many distressed cancer patients do not make use of psychosocial care and as a result psychological comorbidity is often undertreated in cancer patients. Barriers to referral to psychosocial care are insufficient screening for anxiety and depression at the often busy clinics, costs, and a lack of knowledge about available psychosocial services on the part of both care providers and patients. A comprehensive and integrated organization of psychosocial care, such as stepped care, might be an effective method to tackle undertreatment of distress in cancer patients.

Stepped care is a care program based on clinically proven, best-practice pathways to care over a series of steps. The steps targeting psychological distress usually involve watchful waiting, guided self-help and other brief therapies, followed by more intensive psychological interventions or medication. In stepped care, more intensive treatments are generally reserved for people who do not benefit from simpler first-line treatments, or for those who can be accurately predicted not to benefit from such treatments. The results of treatments are monitored systematically, and changes are made (‘stepping up’) if current treatments are not achieving a significant health gain.

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, efficacy of stepped care, and self-management and eHealth.

Chapter 2 described a meta-analysis on the prevalence of depression and depressive symptoms in cancer patients during or after treatment. Pooled mean prevalence of (symptoms of) depression in cancer patients in non-palliative care settings during or after treatment ranged between 8% and 24% and depended on the instruments used, type of cancer and treatment phase. Structured diagnostic interviews were used to assess depression in 49 studies. Cut-off scores of the Hospital Anxiety and Depression Scale-depression subscale (HADS-D ≥ 8 or HADS-D ≥ 11), and of the Center for Epidemiologic Studies (CES-D ≥ 16) were used to assess depressive symptoms in 66, 53 and 35 studies, respectively. Mean prevalence of depression was 13%. Mean prevalence of depressive symptoms was 17%, 8%, 24%, respectively.
Prevalence of (symptoms of) depression ranged from 3% in patients with lung cancer to 31% in patients with cancer of the digestive tract. Prevalence of (symptoms of) depression was highest during treatment: 14%, measured by diagnostic interviews, and 27%, measured by self-report instruments. In the first year after diagnosis, prevalence of (symptoms of) depression measured with diagnostic interviews and self-report instruments was 9% and 21%, respectively, and 8% and 15% longer than 1 year after diagnosis.

In Chapter 3, the added value of screening in follow-up care to identify HNC patients with untreated psychological distress was examined. Screening for distress has added value because of the patients who screened positively for psychological distress (29%), the majority (82%) did not yet receive treatment. Patients who received psychological or psychiatric treatment had a significantly higher score on the HADS total scale, a lower (worse) score on the EORTC QLQ-C30 scale emotional functioning, a higher (worse) score on fatigue, and on the EORTC QLQ-H&N35 scales oral pain, speech problems and less sexuality.

Chapter 4 described the study protocol of a randomized clinical trial by means of which the efficacy of a stepped care strategy targeting psychological distress in HNC and LC patients was examined. The stepped care model included watchful waiting, guided self-help via Internet or a booklet, brief face-to-face problem-solving therapy, and specialized interventions such as cognitive behavioral therapy and/or antidepressant medication. Stepping up to the next treatment was mandated when a patient’s score on the HADS total scale remained above 7. In the control group patients received care as usual.

Chapter 5 presented the results of this randomized controlled trial. The main finding of this study was that SC is effective to reduce distress and improve HRQOL among HNC and possibly LC patients with untreated psychological distress. The course of psychological distress from baseline to 12 months follow-up was significantly better for the intervention group compared with the control group. Effect sizes at separate time points revealed moderate to strong effects of SC on psychological distress and several HRQOL aspects post-treatment and at short-term follow-up, but no longer at 12 months follow-up (decay effect). Also, the recovery rate was significantly higher post-treatment (55% in the intervention group vs. 29% in the control group) but not at 12 months
follow-up (46% vs. 37%, respectively). The stepped care model was especially effective for patients with depression as assessed with the CIDI psychiatric interview, compared with patients with depressive symptoms only. It is concluded that SC speeds up recovery of distress and improvement of HRQOL.

In Chapter 6, HNC and LC patients’ motivation to start a guided self-help intervention (based on problem-solving therapy, step 2 in the stepped care model) targeting psychological distress, experiences with the intervention, and the perceived outcomes were qualitatively explored. Patients participated in the intervention for intrinsic (e.g., to help oneself) and for extrinsic reasons (e.g., being asked by a care professional or to help improve health care). Participants indicated positive and negative experiences with the intervention. Several participants appreciated participating as being a pleasant way to work on oneself, while others described participating as too confrontational. Some expressed their disappointment as they felt the intervention had brought them nothing or indicated that they felt worse temporarily, but most participants perceived positive outcomes of the intervention (e.g., feeling less distressed and having learned what really matters in life for them).

Finally, in Chapter 7, the main findings of this thesis were discussed, clinical implications were addressed, and recommendations for future research were given. It is concluded that 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.