Summary

Chapter 1 provides the background, aims and outline of this thesis. It presents changes in the prevalence and the unfavorable direction of the case fatality rate among Indonesian women with breast cancer. The recent data showed that breast cancer has emerged as the most frequent cancer and the leading cause of death among Indonesian women. Although the incidence rate is lower than in developed countries, the case fatality rate from breast cancer is remarkably high. Similar with others South East Asian countries, the poorer survival among Indonesian breast cancer patients is largely due to late presentation of the disease. This is caused by many factors, such as a lack of facilities for early detection and a poor access to primary treatment. As cancer is a chronic and frequently terminal disease, women who are diagnosed with breast cancer are confronted with multiple stressors throughout their illness trajectory. Therefore, understanding psychological adjustment and potential psychosocial factors that related to non-adherence to medical recommendation in women with breast cancer is urgently needed.

The objective of this thesis was to identify possible psychosocial risk factors for non-adherence to treatment and psychological distress in Indonesian women with breast cancer. To answer the objective of this thesis, first we explored potential determinants of non-adherence qualitatively, subsequently we conducted several validations and exploratory studies to better comprehend the nature of psychological problems and adjustment related to breast cancer, and finally we explored the psychological factors that might be associated with non-adherence to treatment quantitatively.

Chapter 2 presents the results of a qualitative study about psychosocial and cultural reasons for delay in seeking help and non-adherence to treatment in Indonesian women with breast cancer. Consecutive fifty breast cancer patients who were treated at the Outpatient Surgical Oncology Clinic were interviewed. The interview included participants’ demographic characteristics and the following topics: knowledge of the disease, perceived disease severity, information provided by the patient’s physician, use of health services and alternative treatment, attitudes towards western and traditional medicine particularly in relation to the patient’s disease, the perceived benefits of, and barriers to, treatment and non-adherence to medical recommendations. Interviews were recorded, transcribed verbatim and coded using qualitative software program ATLAS.ti version 5.2. Eight main themes concerning reasons for delay in seeking medical help and treatment non-adherence emerged, namely: lack of
awareness and knowledge, cancer beliefs, treatment beliefs, financial problems, emotional burden, severe side effects, paternalistic style of communication and unmet information needs. This study found several modifiable psychosocial and cultural factors that may be used to develop interventions to reduce non-adherence behavior in this population. These findings suggest that the provision of extensive information through media campaigns, treatment decision aids, and caregiver and patient education are needed to change the illness behaviors of Indonesian breast cancer patients.

In Chapter 3, we aimed to translate the Distress Thermometer (DT) into Indonesian, test its validity in Indonesian women with breast cancer and determine norm scores of the Indonesian DT for clinically relevant distress. We translated the original version of the DT into Indonesian version using a forward and backward translation procedure according to the guidelines. Therefore, one-hundred and twenty breast cancer patients at the Outpatient Surgical Oncology Clinic completed a standard socio-demographic form, the DT and the Problem List, the Hospital Anxiety and Depression Scale (HADS) and the WHO Quality of Life (WHOQOL-Bref). The receiver operating characteristic curve analysis identified a good discrimination (AUC=0.81) of the DT cutoff score relative to the established cutoff score of the HADS \( \geq 15 \), and a cutoff score of 5 on the DT had the best sensitivity and specificity. Patients who reported distress above this cutoff experienced more problems in the practical, family, emotional, spiritual/religious and physical domains than patients below the cutoff score. In addition, patients at advanced stages of cancer experienced more emotional and physical problems. Patient’s distress level was negatively correlated with overall quality of life, general health and all quality of life domains. We conclude that the DT was a valid tool for screening distress in Indonesian breast cancer patients, and we recommend using a cutoff score of 5 in this population. A particular finding of this study was the positive association between clinically significant distress and spiritual/religious concerns, which is similar to the results of a study conducted in Korea, but in contrast to most studies conducted in Western countries that found no association or only weak association. We conclude that patients in an advanced stage of cancer should be given priority for psychological intervention.

Chapter 4 investigates whether Indonesian women with breast cancer have higher external Health Locus of Control (HLC) than healthy women, and explores the association between HLC and symptoms of anxiety and depression. In this study, one-hundred and twenty consecutive women with breast cancer who were recruited at the outpatient surgical oncology
clinic completed a standard demographic form, Form C of the Multidimensional Health Locus of Control, as well as the Hospital Anxiety and Depression Scale. As a comparison group, one hundred and twenty two healthy women who were recruited from the Bandung area completed a standard demographic form and the Form C of the Multidimensional Health Locus of Control. Women with breast cancer had higher scores on all external HLC subscales, i.e. chance, doctor, powerful others and God, and lower internal HLC compared to healthy women. Lower education level was associated with higher chance HLC scores in women with breast cancer, and was associated with lower internal HLC and higher chance HLC in healthy women. Time since diagnosis was significantly negatively correlated with God LHC scores. High God LHC scores were associated with a high level of anxiety, whereas none of the HLC subscales were associated with depression. Our results suggest that a strong belief in an external source of control, i.e. God, might be negatively associated with patients’ emotional adjustment. Further research is needed to give an insight into the direction of this association.

In Chapter 5, breast cancer patients’ level of satisfaction with information on illness and treatment and its association with illness perceptions and quality of life were studied. Seventy consecutive breast cancer patients at the Outpatient Surgical Oncology Clinic completed a demographic form, the Satisfaction with Cancer Information Profile, the Brief Illness Perception Questionnaire and the World Health Organization Quality of Life. A considerable number of patients (41%-86%) reported that they received insufficient information regarding several aspects related to their illness and treatment, particularly information about access to patient support groups and the impact of their treatment on long-term quality of life. In regard to the type and timing of information, the majority of patients were dissatisfied with the amount of written information provided. Patients’ satisfaction with the type and timing of information was positively associated with stronger beliefs in personal control, less concerns about their health condition, better understanding of their illness, and satisfied patients were less emotionally affected by their illness. Satisfaction with the type and timing of information was also associated with a more positive perception of their general health and a better psychological health condition. On the other hand, satisfaction with the amount and content of information was not associated with illness perception and quality of life. Our study results suggest that satisfaction with information provided is associated with better health outcomes, including more positive illness perceptions; therefore it highlights the importance of providing adequate and sufficient information that meets the needs of patients. Even though, longitudinal studies are needed to determine whether there is support for this interpretation.
The study in Chapter 6 evaluates the association between psychosocial factors (i.e. knowledge, illness perceptions, health locus of control, satisfaction with information and distress) and non-adherence to treatment in Indonesian women with breast cancer. Seventy consecutive breast cancer patients participated in this study. They completed a demographic form, the non-adherence questionnaire, the Breast Cancer Knowledge Test, the Brief Illness Perception Questionnaire, the Multidimensional Health Locus of Control Scales, the Satisfaction with Cancer Information Profile and the Distress Thermometer. Seventeen (24%) out of seventy patients reported that they had delayed initiating treatment at the hospital, and nine (13%) out of seventy patients had missed two or more consecutive treatment sessions. The multivariate regression analyses showed that having a negative view of cancer (i.e. a view with the emphasis on its threatening character) was associated with missing treatment sessions, whereas having consulted a traditional healer was associated with both treatment delay and missed treatment sessions. Contrary to our expectations, patients’ knowledge, health locus of control and satisfaction with information was not associated with treatment delay and missed treatment sessions. We suggest that health professionals need to be aware of patients’ negative illness perceptions and unrealistic beliefs in traditional healers, and provide them with clear information about their illness and its treatment. However, the relative importance of these factors should be studied in future prospective studies, also considering the exploratory character of this study.

Finally, Chapter 7 provides a general discussion of the findings, discusses the accumulated results which related to our research aims, and presents implications for clinical practice and future research. The studies presented in this thesis identified several cultural differences in psychological factors associated with non-adherence to treatment and psychological adjustment compared to the Western cancer population, namely: Indonesian women with breast cancer had higher belief that God determines their health conditions, were more dissatisfied with several aspects of information provided by the health care professionals (e.g. information about social/financial support and the provision of written information) and had a stronger belief in traditional healers.

Screening for psychological distress among women with breast cancer is needed in daily cancer care services to prevent potential severe psychological problems and provide additional psychological interventions to patients who need it. Health professionals need to be aware of patients’ negative illness perceptions and a strong belief in traditional healers, factors which were associated with treatment delay and non-adherence to treatment. Provision of clear,
concise and easy to understand written information about illness and its treatment (e.g. leaflets) can be a cost-effective and efficient source of information supplementing the verbal information in the busy setting of the oncology clinic in Indonesia. At this moment, we develop a psycho-education intervention program that aims to diminish delay in seeking help and treatment delay, and increase treatment adherence in Indonesian women with breast cancer.