English summary

The neuropsychiatric disorder Korsakoff syndrome (KS) is caused by thiamine deficiency, which in particular occurs among alcoholics. This disorder is characterized by severe cognitive deficits: both long-term memory and executive functioning are affected, accompanied by confabulations. In the Netherlands, there is a long tradition of nursing home care for people with severe forms of KS. Professional caregivers working in these nursing homes experience in daily practice that residents with KS also exhibit a variety of behavioural symptoms and a lack of awareness of deficits. These features challenge the skills and capacity of caregivers in supporting these residents. However, scientific knowledge about the care of people with KS is scarce. Therefore, the overarching goal of this study was to achieve a better understanding of the long-term care for people with KS with specific attention to behavioural symptoms and awareness of functional deficits. We carried out a retrospective chart review on the characteristics, comorbidity and use of psychotropic drugs in people with KS living in nursing homes. We reviewed the literature with regard to behavioural symptoms in people with KS. We performed a cross-sectional, observational study that focused on: 1) the prevalence and severity of neuropsychiatric symptoms, and associated caregiver distress, and 2) awareness of functional deficits and its relationships with neuropsychiatric symptoms. Finally, in a qualitative study we explored the perspectives of professional caregivers on good care for residents with KS. We summarize the results from these studies in the next sections.

As there is no generally accepted definition of KS and there are no generally accepted criteria for the diagnosis of KS the term KS is used as an umbrella term to indicate both KS and other alcohol-related cognitive disorders.

Chapter 2: Characteristics, comorbidity and use of psychotropic drugs in nursing home residents with KS

In a retrospective chart review 556 people with KS living in ten specialized nursing homes participated. The majority of residents were men (75%) with a mean age of 57 years at the time of admission. Residents were mainly divorced, single or widowed (88%). The mean length of stay was 6 years. These findings showed that nursing home residents with KS are a specific subgroup in the nursing home: they are much younger, more often male and stay for a longer period in the nursing home than the general nursing home population. Somatic and psychiatric comorbid disorders were common. Psychotropic drugs were prescribed to a substantial proportion of 71% of the residents with a wide variation in prescription patterns among the participating nursing homes. In particular, antipsychotics were prescribed very often (48%). This can
be partly explained by the prevalence of psychiatric disorders. We hypothesize that these prescriptions are partially inappropriate, which means that they are probably used for an unapproved indication, such as the treatment of challenging behaviour.

Chapter 3: Prevalence and severity of behavioural symptoms in people with KS: what is already known?
A systematic literature review demonstrated that good quality studies on behavioural symptoms in people with KS were lacking. The fifteen included studies showed that behavioural symptoms frequently occur. The most prevalent behavioural symptoms were depressive symptoms and disorders (2 to 50%, median 27%) and agitation and aggression (10 to 54%, median 27%). Severity estimates were all below pathological thresholds. The highest severity estimates were found for apathy. Due to low quality and heterogeneity of the included studies, these results have to be interpreted with caution.

Chapter 4: Prevalence and severity of neuropsychiatric symptoms and associated caregiver distress in nursing home residents with KS
In a cross-sectional, observational study neuropsychiatric symptoms (NPS) and associated caregiver distress were assessed with the Neuropsychiatric Inventory-Questionnaire (NPI-Q) and Neuropsychiatric Inventory-Distress Scale (NPI-D) during interviews with nurses or nurse-assistants. A total of 281 participants were recruited from nine nursing homes providing specialized care to KS residents. Almost all residents (96%) showed at least one NPS and nearly half of the residents (46%) showed five or more symptoms. Furthermore, irritability/lability (68%), agitation/aggression (59%), and disinhibition (53%) were most prevalent, whereas hallucinations (9%) were relatively rare. Delusions (32%) were remarkably more prevalent than hallucinations. We hypothesized that this could be partly attributed to a disturbance of reality monitoring. Despite high prevalence rates, NPS were on average not severe. In about half of the residents (49%) one of the NPS was severe to residents. Nurses and nurse assistants also reported low levels of distress related to the NPS. Only a small proportion of residents (11%) showed at least one NPS that was associated with high distress for the nurse or nurse assistant. The most prevalent NPS were also most severe and most distressing for professional caregivers. An important explanation for the low severity and distress may be the fact that all residents were living in specialized nursing homes in which the care is tailored to their specific needs and professional caregivers are used to cope with NPS.
Chapter 5: Prevalence and the level of impaired awareness of functional deficits, and its relationships with neuropsychiatric symptoms in nursing home residents with KS

In the same cross-sectional, observational study as described in chapter 4, awareness of functional deficits was measured. For this purpose the Patient Competency Rating Scale (PCRS) was used. This instrument assesses competencies of daily life functioning and uses a resident versus a nurse rating discrepancy method to indicate the level of impaired awareness. Many KS residents (71%) overestimated their functional capacities. Awareness was most severely impaired for the cognitive domain and the least impaired for the interpersonal/emotional domain. On average, the level of awareness in performing everyday tasks was moderately impaired. The tasks ‘taking care of finances’, ‘scheduling daily activities’ and ‘taking care of personal hygiene’ were most frequently overestimated. Furthermore, apathy was more severe in residents with moderate impaired awareness than in residents who were not or mild impaired. No associations were found between the level of awareness and other NPS. These results confirm previous reports and support clinical experiences that awareness of functional deficits is impaired in many people with KS. We recommend to adequately recognize resident’s level of awareness of functional deficits.

Chapter 6: Perspectives of professional caregivers on good care for nursing home residents with KS

In a qualitative study semi-structured interviews were performed with twelve professional caregivers. By thematic analysis of these interviews it emerged that three perspectives on good care exist among professional caregivers: 1) making daily life a joint effort; 2) being steadfast; and 3) treating with respect. These perspectives include the way in which professional caregivers try to achieve responsiveness as the central challenge in the care for residents with KS is to create that responsiveness. The first perspective entails that the relevant professional caregivers consider it to be their main task to ensure that the residents have the best life possible; it is more important for something to succeed than for the resident to have managed it all by themselves. These caregivers believe that they should help the resident in all facets of daily life. In the second perspective, good care primarily means that the professional caregiver is consistent in limiting intolerable behaviour (such as self-neglect, aggression and sexual disinhibition). Being steadfast provides safety and helps to establish patterns. For these caregivers it is important to retain their distance from the resident. The third perspective stresses that professional caregivers should take residents seriously and, when possible, treat them as they would like to be treated themselves. The caregivers with this view strive for equality in the relationship with the resident, and try to understand the behaviour of the resident. The perspectives reflect fundamentally different views on two themes: 1) the care relationship (balance between
distance and involvement; and the degree of equality) and 2) resident’s autonomy. By elucidating these perspectives, we hope to encourage the practitioners’ reflection on their own ideas of good care for people with KS and their style of caregiving.

**Chapter 7: General discussion and conclusions**

This chapter provides reflections on the main findings, describes some methodological considerations and highlights implications for practice and future research. This thesis showed that: 1) nursing home residents with KS are a specific subgroup in the long-term care that differs from the general nursing home population. This requires appropriate and specialist nursing home care for this group of residents; 2) psychotropic drugs, and in particular antipsychotics, are prescribed extensively. We recommend a structured and multidisciplinary approach to optimize the management of behavioural symptoms and to improve the appropriateness of prescribing psychotropic drugs for people with KS; 3) many residents with KS overestimate their functional capacities. To prevent them from being over asked, it is important that professional caregivers recognize and regularly evaluate resident’s level of awareness of functional deficits in the daily care; and 4) professional caregivers have different perspectives on good care and how to achieve responsiveness in residents with KS. Intervision sessions can help to start the conversation with each other and to stimulate caregivers to become more aware of their own perspective on good care and their own style of caregiving. Further research will have to reveal whether this will enhance their performance. Additional research should include: 1) the implementation and evaluation of a multidisciplinary care program for the management of behavioural symptoms; 2) the appropriateness of psychotropic drug prescriptions; and 3) the conceptualisation and the assessment method of awareness, and which clinical approaches and (psychosocial) interventions are effective to deal with impaired awareness in people with KS.

For the first time a comprehensive insight into the characteristics of people with KS living in nursing homes is provided. The findings of this thesis may be a starting point for further research on the long-term care for these people and for the development of an evidence based care program. This may help professional caregivers to better support the complex needs for nursing home residents with KS, and ultimately, improve the quality of care.