Summary
This thesis focuses on the evaluation and implementation of personalized psychosocial interventions for people with dementia and their caregivers in the community. We searched existing literature to investigate which subgroups benefit from which interventions, evaluated several examples of personalized care interventions including the implementation issues of these interventions, and we composed an evidence-based implementation model based on the literature and our study results that can be used to promote, structure and guide the implementation of personalized psychosocial interventions in dementia care practice.

Chapter 1 describes the background and rationale for the studies reported on in this thesis and describes the aims of our research. The continuing increase in the number of people with dementia puts severe pressure on the available care and support services for this target group. As the amount of professional care will not rise at the same rate as the number of people with dementia, more support than they already give will be necessary from informal caregivers. In order for them to cope with their caregiver role, informal caregivers need adequate support, as do people with dementia to help them deal with living with dementia. Psychosocial interventions can provide such support and they are aimed at improving quality of life by supporting people with dementia and informal caregivers in dealing with the consequences of dementia, reducing mental health problems, such as depression and anxiety, reducing behavioral problems and improving cognitive functioning in people with dementia or reducing the speed of decline. To increase positive outcomes of psychosocial interventions, they need to be tailored to the individual needs and characteristics of people with dementia and informal caregivers. It is also important to know if subgroups of people with dementia and informal caregivers benefit more from certain interventions. Although past studies have focused on the effects of personalized care interventions, they were mainly aimed at the institutional setting. Similar studies conducted in the community setting are difficult to find. Furthermore, in order for effective interventions to find their way into dementia care practice, successful implementation is necessary. This requires the use of effective implementation strategies that can be derived from process evaluations conducted when newly developed psychosocial care interventions are applied in practice.

Chapters 2 and 3 describe the results of a systematic literature review on the relationship between characteristics of people with dementia and informal caregivers and the effectiveness of psychosocial interventions. We searched the electronic databases of PubMed, psycINFO and Cinahl for reviews published between January 1990 and February 2008 that report on effective psychosocial
interventions for people with dementia and informal caregivers. We were able to trace and include 71 studies regarding psychosocial interventions for people with dementia of which 26 were based in the community setting. With regard to psychosocial interventions for informal caregivers we traced 26 studies. Outcomes of these studies were categorized based on characteristics and identified subgroups as well as outcome measures on which effects were found. Several characteristics were found to be related to positive outcomes of interventions. For people with dementia living at home these were the type and severity of dementia, and living with their informal caregiver. These characteristics were most often related to the outcome categories of cognitive functioning and behavioral functioning.

Characteristics that were frequently related to positive outcomes for informal caregivers were gender of the caregiver, the presence of mental health problems (such as high levels of depression or high anger expression) before the start of the intervention and the previously named characteristics of people with dementia. Outcome categories that these characteristics were most frequently related to were mental health problems (such as a decrease in depression or anxiety) and caregiver sense of competence and burden. The results of these reviews provide a first overview regarding which subgroups of people with dementia and informal caregivers benefit from which type(s) of intervention(s) and can help professional caregivers better attune care and welfare services to their clients. Our results also indicate that more subgroup research should be conducted as part of effect studies on psychosocial interventions and that post-hoc subgroup analyses should become a standard part of effect evaluation studies.

Chapter 4 reports on the results of a cluster randomized trial to evaluate the effect of DEM-DISC (Digital Interactive Social Chart) that aims to support informal caregivers in finding appropriate care and welfare services based on their needs and personal characteristics. The goal of the study was to further develop DEM-DISC and to evaluate the effects on needs of informal caregivers and people with dementia, as well as to evaluate its user-friendliness and usefulness to informal caregivers and case managers who had access to the system for 12 months. 41 informal and 13 formal caregivers could use DEM-DISC during this period. Controls were 32 informal and 14 formal caregivers. The informal caregivers from both groups received case management. The user-friendliness and ease of use of DEM-DISC was evaluated positively by both informal and formal caregivers. The results on the different outcome measures were mixed. Informal caregivers who used DEM-DISC reported an increased sense of competence after 12 months compared to controls. However, after 12 months of use they also reported more needs in total, including more unmet needs compared to controls. A possible explanation is
the fact that the available information in DEM-DISC made them realize they had needs in areas they were not previously aware of. Informal caregivers who accessed the system more frequently than others did report more met needs after 6 months compared to informal caregivers who did not have access. This subgroup of high frequent users was characterized by having more mental health problems, more often not having a paid job and being older than informal caregivers who accessed DEM-DISC less frequently. No effects were found on the secondary outcome measures in informal caregivers. Based on the results of this study, we can conclude that informal caregivers who experience mental health problems, do not have a paid job and are older, are likely to benefit from using DEM-DISC.

The expected feasibility of future nation-wide implementation of DEM-DISC was explored as well by conducting interviews with 10 stakeholders. Important themes that were revealed that could impact the further implementation were the ability to keep the information regarding care and welfare services in the system up to date, the ability to raise support among important collaboration partners and investors, and the way in which clients are referred to DEM-DISC. Future research should further investigate these themes and compile a viable business case to implement DEM-DISC.

Chapter 5 describes the results of the evaluation of Dementelcoach, a telephone intervention that offers emotional, social and practical support to informal caregivers of people with dementia living at home. Coaching was provided by trained professional caregivers to 21 informal caregivers who received telecoaching only (experimental group 1) as well as to 25 informal caregivers who also received day care for the person with dementia (experimental group 2). These groups were compared with each other as well as with a comparison control group of 8 informal caregivers of persons with dementia who had recently started psychogeriatric day care, but who did not receive individual support or coaching. In both experimental groups, coaching was given every two to three weeks for a period of twenty weeks. The results showed that informal caregivers who received coaching in addition to psychogeriatric day care experienced less burden compared to informal caregivers who received telecoaching only. This group also reported fewer mental health problems than informal caregivers who received day care only. These results argue in favor of providing combined support aimed at both the informal caregiver and the person with dementia. Telecoaching provides personalized care tailored to specific problems that are experienced by caregivers and can provide an effective and efficient solution for a large group of caregivers who do not have access to, or are not willing to use, other care support services outside their homes.
Chapter 6 reports on the process evaluation that was conducted to investigate the implementation of two case management models in the Netherlands: the linkage model and the combined intensive case management/joint agency model (in the linkage model the dementia care network comprises multiple case management providers whereas in the intensive model there is only one independent case management organization). Twenty-two stakeholders were interviewed representing eight stakeholder perspectives in both models (i.e. case managers, project leaders, municipalities, insurance companies). The results of the process evaluation support the implementation of the intensive case management model. While stakeholders in the intensive model primarily reported on aspects that had facilitated the implementation of case management, stakeholders from the linkage model focused more on the barriers that had impeded the implementation. We found that case managers in the intensive model are better able to provide quality of care to their clients as they are more closely connected to an expert team than case managers in the linkage model. Also, they do not have to deal with competing case management providers, as the intensive model allows for only one independent case management organization. In the linkage model, the presence of competing care providers caused many collaboration problems, which affected the entire implementation process. Although this study advocates the implementation of the intensive case management model, regional differences and the way in which dementia care is organized in those regions might not always clear the way for this model. Policy recommendations are needed to further stimulate the development of case management towards a more uniform model, similar to the intensive model, in which case managers closely collaborate with other care professionals to promote integrated dementia care.

Chapter 7 describes the evaluation of a qualitative explorative pilot study into follow-up visits in the nursing home by community psychiatric nurses of the mental health care service, which aim to improve the transfer of people with dementia and severe behavioral problems to the nursing home. During the follow-up visit nursing home caregivers were provided with advice on how to deal with behavioral problems of the client as well as with biographical information. Community psychiatric nurses also provided support to the informal caregivers by means of a visit or a final telephone conversation after nursing home placement of the person with dementia. We conducted interviews with 5 informal caregivers, 12 nursing home professionals and 4 community psychiatric nurses about 14 clients admitted to the nursing home, to obtain insight into their experiences with the follow-up visit. We also conducted semi-structured interviews with 11 stakeholders about the possibility of future implementation of the follow-up visits. Nursing home caregivers felt the follow-up visit was too late to meet the purpose of providing them with
information about problem behaviors. They had frequently already discussed these with the intramural multidisciplinary team. However, they valued the biographical information, which helped them to better attune care to personal needs of their client. Informal caregivers reported that the final conversation with the community psychiatric nurse helped them to bring the care period prior to admission to a conclusion. The future implementation of the follow-up visit is expected to be challenging. Community psychiatric nurses as well as nursing home caregivers and the organizations where they work require a change in the way they work (incorporating a follow-up visit as a standard procedure when a client is admitted to the nursing home) and should be more open to collaboration. Continuous changes in financing for both mental health care organizations and nursing homes, and cultural differences between the extramural and intramural setting form barriers as well. Future studies are encouraged to evaluate the effect of the follow-up visit on people with dementia and informal caregivers to contribute to the improvement of continuity of care when people with dementia are institutionalized and to improve the transition to the nursing home setting.

Chapter 8 focuses on the construction of an evidence-based model for the implementation of personalized care interventions for people with dementia and informal caregivers living in the community. The framework of this model was based on the Theoretical model for adaptive implementation, which we also used as a framework for the process analysis in our empirical studies. The content of the model for implementation of personalized care interventions was based on a synthesis of the studies described in chapters 2 through 7. Our model provides a checklist for researchers, professional caregivers and policy makers who wish to develop, evaluate or implement personalized care interventions. It comprises essential elements for the implementation of personalized care, including important considerations and potential barriers to these elements. The model addresses several issues: how personalized care interventions should be offered; to whom they should be offered; if they are adaptable to personal characteristics and needs of clients and informal caregivers; if both organizational management and staff that provide the intervention support personalized care and are able to focus on providing individualized care; continuity of care aspects, collaboration among care professionals and organizations; and law and legislation aspects of personalized care. Although the content of the model is mainly based on our own research in community-based care, many results confirm the findings of other studies that investigated the implementation of personalized care in the community and nursing home, as became clear when we reviewed the literature on this subject. The use of this new evidence-based implementation model is recommended for all relevant
PARTIES AND SHOULD BECOME THE NEW STANDARD OR GUIDELINE FOR IMPLEMENTATION OF PERSONALIZED DEMENTIA CARE INITIATIVES IN THE COMMUNITY.

Chapter 9 is a reflection on our findings and discusses methodological issues, the scientific, clinical and societal relevance of the conducted studies, and it presents recommendations for future research and practice. This thesis has shown the importance and effects of personalized psychosocial care interventions for people with dementia and informal caregivers. The studies we conducted and reported on were driven by the expected increase in the number of people with dementia along with an expected relative decrease in the number of professional caregivers, and the need to more adequately support people with dementia and their informal caregivers. This support will greatly benefit from knowledge on which subgroups benefit from which interventions. Multi-component interventions that are adaptable to individual needs and include aspects of self-management outline what is important for future dementia care practice. The implementation and long-term sustainability of these interventions of personalized psychosocial care can be facilitated and ensured by considering essential elements throughout the implementation process. It is proposed that future research into the effects of psychosocial care interventions should incorporate subgroup research, and that future development of interventions is directed towards individualized care for people with dementia and informal caregivers. It is also recommended to use the evidence-based model for implementing personalized care that is derived from this study to promote embedding proven effective personalized psychosocial interventions in dementia care practice.